Toward A National Health Information Infrastructure:

A Key Strategy for Improving Quality in Long-Term Care

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Executive Summary

The availability of detailed and clinically relevant data is essential for clinical care decisions and essential for oversight groups making decisions related to the quality of that care. The Institute of Medicine has repeatedly emphasized that cost-effective, high quality health care is linked to the availability of information, and that computerized patient medical record information systems are an essential strategy in improving the quality of care. A National Health Information Infrastructure (NHII) has been identified by numerous advisory panels and experts as essential for improving patient safety and quality, controlling rising health care costs, and responding to health care crises (e.g., bioterrorist attacks). The technology to support the NHII is available. Implementation awaits a coordinated national effort, particularly around health information standards.

The purpose of the NHII is to share information and knowledge when and where needed. An essential building block of the NHII is adoption and use of agreed upon terminology and messaging standards. Terminology standards provide an unambiguous, machine-readable meaning of specific terms. Messaging standards permit the electronic exchange of information in a consistent format. Terminology and messaging standards will allow the inter-operable use and exchange of healthcare information. Much of the discussion about electronic health information standards has arisen within the acute care arena. In long-term care, there has been limited discussion related to electronic health information standards.

There were three objectives of this study. The first objective was to determine, as a pilot activity, whether leading terminology and classification systems provided content coverage to support clinical decision-making and quality of care oversight in nursing homes as recommended by clinical experts and as reflected in the literature. The three domain areas of pressure ulcers, chronic pain, and urinary incontinence provided the focus of this content coverage study. The second objective of this study was to examine the content of the federally required nursing home

minimum data set (MDS) to determine whether it provides the information needed to understand quality of care in nursing homes in the three selected domains. Third, the study also examined the extent to which the content of MDS was captured by the three terminology systems described below.

Nursing homes are presently required to complete the nursing home MDS at numerous points during a resident's stay in a nursing facility. MDS data is used for several regulatory purposes including supporting the Medicare and sometimes Medicaid nursing facility payment methods and developing nursing home quality indicators and quality measures.

One formal terminology system and two classification systems were examined in this study: the Systematized Nomenclature of Medicine – Clinical Terms (SNOMED CT), International Classification of Functioning (ICF), and International Classification of Nursing Practice (ICNP). SNOMED CT was developed specifically as a comprehensive, detailed clinical terminology system, and is structured in a way that takes advantage of new computer-based technologies for clinical information systems. SNOMED CT was selected for this study because it is considered to be the most comprehensive terminology system. Given the scope of clinical terms included in SNOMED CT and its acceptance by healthcare providers, the federal government is pursuing an agreement with the developers of this terminology that would make SNOMED CT widely available for use within the U.S. In contrast to SNOMED CT, ICF and ICNP were developed as classification systems, not detailed clinical terminologies. The ICF classifies many terms related to disability, an issue that many nursing home residents and that providers must address. The ICNP emphasizes the classification of terms relevant to nursing practice, a discipline very important to nursing home services.

The terms, data elements, and concepts needed to understand nursing home quality in the three domains were obtained through consultation with nationally recognized experts in each of the domains and a review of the literature.

Regarding the first objective, this report demonstrates that a comprehensive, internationally recognized formal terminology system such as SNOMED CT provides relatively complete coverage of terms suggested by the experts and the literature as needed to understand quality in the domains of pain, incontinence and pressure ulcers. Specifically, the study found the following complete match rates of terms in SNOMED CT and the terms recommended by experts: 77% for pressure ulcers, 92% for chronic pain, and 95% for urinary incontinence.

The ICF and the ICNP did not provide nearly as comprehensive coverage as SNOMED CT. The ICF was found to have the following complete match rates of the terms suggested by experts: 18%, 4%, and 4% for the domains of pressure ulcers, pain, and incontinence, respectively. The ICNP was found to perform equally poorly, with the following complete match rates of the terms suggested by experts: 16%, 3%, and 4% for the domains of pressure ulcers, pain, and incontinence, respectively. The differences between the content coverage provided by SNOMED CT and both ICF and ICNP illustrate why *comprehensive, detailed* clinical terminologies are essential components of the NHII. If clinically relevant data are captured at the point of care and encoded using a reference terminology system, algorithms can be written that enable the derivation of more use-specific classifications or reports (e.g., ICF, ICNP, or MDS). Perhaps more importantly, clinical data collected at the point of care can also be made available for "real time" applications such as automated alerts and clinical decision support systems, an important strategy for improving the quality of care. Clinical data, entered once at the point of care and encoded using a reference terminology system, are then said to be "re-usable" for multiple applications.

With respect to the second objective, the report indicates that the design and content of the MDS reflect the technology available at the time the MDS was originally developed. The report describes the MDS as an enumerated coding scheme that was designed to meet predefined needs for clinical data and information, and, as such, is not based on any standardized terminology system (i.e., a coding scheme that would permit the unambiguous exchange of information across the healthcare continuum).

The study found the nursing home MDS provided very limited coverage of terms suggested by experts as needed to understand nursing home quality in the domains of pain and incontinence. Overall, in the domains of incontinence and pain, fewer than 10% of the terms suggested by the clinical experts and literature as needed to understand nursing home quality had a complete match in the MDS. The MDS performed better with respect to pressure ulcers. The MDS provides an exact match for 70% of the pressure ulcer terms identified by the clinical experts and the literature needed to understand nursing home quality. Overall, this report concludes that the MDS does not capture information the experts said would be needed to measure nursing home quality in the three domains.

Finally regarding the third objective, most of the information collected using the MDS is not captured by SNOMED CT, ICF, or ICNP. Specifically, with respect to the extent to which SNOMED CT included any of the terms in the MDS, SNOMED CT was found to provide a complete match for 46% of the MDS terms. The ICF and ICNP were found to provide almost no coverage of the terms included on the MDS. Overall, a complete match rate of terms in the MDS and those in the ICF and ICNP was found 2% and 12% of the time, respectively.

Today, health information systems are expected to meet a variety of changing demands for data and information to support many purposes (e.g., automated alerts, decision support, quality monitoring, payment policy, and outcomes research). Standardized terminology systems are es-

sential to permit the use and exchange of clinical data across applications and systems. Given point of care documentation, technology is now available to build electronic health information systems that will efficiently meet a variety of needs including: providing immediate feedback to care providers by, for example, issuing alerts related to relevant best practice guidelines, generating data needed for internal and external quality monitoring, exchanging critical patient information in a timely manner across the health care continuum, and reducing provider burden associated with current documentation requirements.

One of the most significant challenges to implementing electronic health information systems is the lack of standards for electronic patient medical record information, especially standards around the terminology that expresses clinical documentation. Achieving the promise of the NHII requires a coordinated national effort to adopt standardized terminologies, permitting the extension of inter-operable electronic health information systems into long-term care. Efforts to develop payment and quality monitoring methods that are derived from clinical documentation systems in long-term care must be consistent with the underpinnings of the NHII. Failure to do so could only continue and exacerbate provider data collection burden and limit the scope, and, therefore, the utility of the NHII as a key strategy for improving the quality of care.

Part One: Toward a National Health Information Infrastructure

There has been growing interest in the use of electronic health information systems. The Secretary of Health and Human Services (HHS), Tommy Thompson, has emphasized as one of his main priorities the use of information technology in healthcare. In November of 2001 the National Committee on Vital and Health Statistics (NCVHS) issued a report to Secretary of HHS that called for Federal leadership in establishing a National Health Information Infrastructure (NHII) (1). That report followed an 18-month period of hearings and consultations with consumers, providers, public health professionals, technology specialists, and policy makers. The first section of this paper provides an overview of the NCVHS report, and is followed by a discussion of the need for standards in order to achieve the goals of the NHII, the critical role of clinical terminologies in patient medical record information (PMRI) systems, and a discussion of the Minimum Data Set (MDS), a component of the Resident Assessment Instrument for Medicare and Medicaid certified nursing facilities in relation to NHII initiatives.

A National Health Information Infrastructure

Demands for readily available health care information have increased dramatically in recent years. Demographic changes such as an aging population with increased chronic illness and a more mobile population have created needs for larger volumes of health information and more easily transferable information. Most recently, concerns about bioterrorism have focused attention on the need for a public health information infrastructure with the capability of providing aggregated information on a real-time basis. The delivery of cost-effective, high quality health care in order to meet national goals for healthy people and healthy populations is now clearly linked to the availability of information.

The NCVHS is a public advisory committee authorized by statute to advise the Secretary of Health and Human Services on national health information policy. It concluded in its NHII re-

port that "implementation of the NHII will have a dramatic impact on the effectiveness, efficiency, and overall quality of health and health care in the U.S." (p. 2). Presently, health information is typically maintained in paper records, in many locations for each patient, including: physician offices, laboratories, hospitals and departments within hospitals (e.g., radiology departments), and with post-acute care providers such as nursing homes and home health agencies. Paper medical records are difficult to read, poorly organized, and are frequently incomplete or unavailable. These problems are particularly pronounced for nursing home patients, who frequently have chronic health conditions and may be transferred to and from providers across the health care continuum.

The vision of the NHII is premised on a foundation of sharing relevant information and knowledge appropriately so that it is available to people when they need it to make the best possible health decisions. The argument put forward by the NCVHS was that with federal leadership as the cornerstone, human, institutional, and technological factors could be developed and brought together in way that enables many forms of communication and support for personal, provider, and public health concerns. The NCVHS report provided examples of how the NHII could improve the quality of health care:

For Consumers

- Real time remote medical consultations wherever the person is located,
- Online search for health information and looking for health care providers,
- Management of one's own health care needs and their health care decision making;

For Providers

- Providing access to more accurate and complete real-time patient data,
- Using clinical guidelines and protocols concurrently with the patient care process,

- Preventing adverse events by providing real time practice warnings to clinicians integrated with the patient care process,

- Supporting continuous quality improvement processes by providing more complete and comprehensive clinical data for outcomes analysis;

For Public Health/Regulators

- Improving the ability to identify, monitor, and respond to health problems,

- Accessing and reporting data needed for public health,

- Increasing the scope, effectiveness, and efficiency of clinical research.

Key characteristics of the NHII include data capture, storage, processing, and presentation of health information, all within secure, confidential environments. Examples of the desired functionality that would result from a fully implemented NHII include:

- Universal use of electronic medical records that capture all health information regardless of the setting in which a patient is receiving services;

- The ability to send and receive messages across health care settings and communities about a patient's health status whenever and wherever needed;

- Automatic electronic reporting to public health for early detection and response to unusual health patterns (such as bioterrorism);

- The provision of real-time clinical decision support (for example, about the efficacy of certain drug treatments or the effectiveness of particular interventions) to health care professionals allowing more rapid widespread application of research findings in routine patient care;

- The ability to aggregate non-identified patient care information to rapidly provide evidence regarding the outcomes and efficacy of health interventions;

- The ability to more accurately and promptly monitor quality of health care services; and

- Reducing the administrative burden on health care practitioners associated with filling out forms, thus allowing providers to focus on delivery of services.

Key to achieving such functionality is point of service documentation in electronic record systems. For example, clinical decision support systems can be developed that "trigger" alerts related to needed assessments or suggest interventions that reflect best practices known to influence quality outcomes. But first, relevant data needs to be documented and coded in a uniform manner so that it can be mapped from the clinical data to an electronic knowledge base.

It is important to recognize that the NHII does not describe a centralized database of patient information. Rather, the vision is for *distributed* health information built on a framework within secure networks with strict confidentiality protections. Given this system architecture, health information could be stored in many locations: electronic record systems in provider offices and health care facilities, organizational databases, personal health cards, etc.

The rapid development and deployment of new information technologies enable data to be captured at the point of acquisition, and then stored, indexed, and retrieved in electronic formats for selective use as required across multiple settings, health care systems, and software applications. This means that if clinical data are carefully structured and encoded in a uniform manner, those data can be electronically transferred, shared, exchanged, and meaningfully used to support a variety of uses such as decision support, quality assessments, individual patient or population surveillance and outcomes analyses, or regulatory reporting. The vision is for the algorithmic retrieval, aggregation, and reuse of data from clinical records to meet multiple needs. Achieving such "interoperability" across systems and applications requires agreement on and adoption of standards for health information systems.

Health Information Standards for Interoperable Health Data

A major impediment to the development of the NHII is the lack of complete and comprehensive standards for electronic patient medical record information (PMRI). In its February 2002 letter to the Secretary of Health and Human Services the NCVHS wrote that "Standards for PMRI are important because they will facilitate significant improvements in the quality of patient care, promote patient safety, control rising healthcare costs, enhance the productivity of clinical re- search and strengthen the nation's ability to detect and respond to healthcare emergencies. They are critical to the creation of a National Health Information Infrastructure" (2).

Data interoperability, or the exchange of consistent and comparable data and information in elec- tronic health information systems, can be accomplished only when developers and vendors adopt and use standards that allow one software program to communicate information to another and when the terms used mean the same thing. Compliance with standards assures that data and in- formation are transmitted and received in a specific, structured form that enables data interopera- bility, comparability, and data quality. Congress demonstrated a commitment to this with the passage of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), requiring standards in connection with electronic payment, and the NCVHS is actively promoting data standards in conjunction with the broader goal of a national health information infrastructure.

For health care information systems, several types of data standards are needed. The emphasis of this project is on terminology. However, a brief discussion of standards related to sending messages in electronic systems and standards related to clinical document architecture standards is provided to highlight the need for coordinated standards in several critical areas in order to en- sure data interoperability.

Messaging Standards

The Health Level Seven (HL7) Messaging Standard Version 2.2 and higher was recommended to the Secretary of Health and Human Services by the NCVHS as the messaging format standards for the PMRI (2). HL7 is a not-for-profit volunteer standards development organization that brings together developers, users, and vendors of electronic health record systems to develop standards that enable the exchange, or interoperability, of data and information across health care applications (www.hl7.org).

HL7 messaging standards specify the technical aspects of sending messages so that one software program can exchange information with another and have that information "understood" by the receiving machine. The format of the current version of the standard was developed for order entry, scheduling, medical record/image management, patient administration, observation reporting, financial management, and patient care transactions. An example of an HL7 ADT transaction message follows (3):

OBX|2|ST|93000.1^VENTRICULAR RATE(EKG)|91|/MIN|60-100<cr>

This message is reporting an observation/result (OBX). Key fields in the message include the value type (string), the observation identifier (93000.1^ventricular rate (EKG)), the observation value (91), the units (beats/minute), and the reference or normal range for this test (60-100). It is important to recognize that HL7 messaging standards only provide for the structure of the message; they do not provide content for that message. The message standard is analogous to an envelope in which one can insert a letter; coded terminologies provide the content of the message.

The HL7 version 3 messaging standard currently under development is of particular interest because, in contrast to specifying the slots into which data and values are inserted as in the example above, version 3 will specify the complex data model (or information model) that carries the

meaning or semantics of the data; HL7 version 3 will provide the syntax for messages that enables the vision of the NHII (i.e., make explicit the semantic and lexical connections that exist within the fields of HL7 messages). The terminologies provide the content of those messages. As a result, it will be technically possible to use data that was recorded at the point of care for multiple purposes, e.g., generating required patient assessment reports from clinical documentation systems.

Clinical Document Architecture Standard

The developing versions of the Clinical Document Architecture (CDA) standard highlight the need for coordinated approaches that will enable the electronic exchange of clinical documents (e.g., progress notes, histories). Also developed by HL7, the CDA standard is heavily dependent on, or leverages, the HL7 message formats mentioned above.

Essentially, a CDA standard is necessary to enable the algorithmic location of pertinent information within current documents, to logically organize documents in document management systems, to categorize information within the document according to a defined structure, and to display documents in electronic systems (including web-based and wireless systems). There is no uniform document structure for paper-based records in long-term care facilities. The lack of a uniform record structure presents significant constraints in deriving data from an electronic record to support reporting requirements such as the MDS.

Three releases of the CDA standard are planned and described by HL7. It is in the HL7 version 3 CDA standard that the format of the electronic medical record and clinical content of electronic documents will be formally specified and modeled using appropriately structured terminology coding systems (www.hl7.org).

The phrase "terminology coding systems" refers to the continuum of approaches used to assure standardized recording and encoding of clinical data in electronic record systems. Such coded data is central to the efficient exchange of information in messages sent across documents, systems and applications. Various types of terminology coding systems exist on a continuum that ranges from human readable, enumerated coding schemes to formal terminologies that enable machine "understanding" (4).

Enumerated coding schemes emphasize encoding *pre-coordinated phrases* that enable users to pick the most relevant terms from pre-defined lists. Typically, such systems provide a very limited coverage of clinical content, and focus only on the specific use for which those data are required. Such systems reflect the technology available 20 years ago and the constraints that were present in relation to coding data for computer based analysis. The MDS is an example of an enumerated coding scheme. The enormous collection of such single-purpose, stand-alone coding systems has created a situation often compared to the Tower of Babel (http://www.tc215wg3.nhs.uk/pages/pdf/vocterm.pdf), where different data sets and software applications are not able to meaningfully exchange or reuse data and information.

More recent research and development initiatives in electronic health records emphasize the use of formal terminologies. Formal terminology systems emphasize the indexing and retrieval of concepts and their associated terms, and the *post-coordination of phrases*.

Between the enumerated classification systems and formal terminologies that anchor this continuum are other types of terminology coding systems such as nomenclatures, classifications, and taxonomies. Each is differentiated by the nature of the organization of terms within the system and the concept orientation of the coding system. It is important to recognize that the development of more complex types of terminology systems is in large part enabled by the development

of technologies that enable more complex data structures and the development and use of description logics based on first order logic as a foundation for the algorithms that enable the semantics or "machine understanding" of text.

The Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) is one of the most extensively developed terminologies of this type (http://www.snomed.org/). SNOMED CT is discussed more extensively below, but an example is provided here to clarify this discussion point. The pre-coordinated term "pneumonia due to Klebsiella pneumoniae" is equivalent to a phrase that could be post-coordinated using the following SNOMED CT codes: 56415008 "Klebsiella pneumoniae" and 233604007 "pneumonia". A portion of the SNOMED CT hierarchy is presented below (5). SNOMED CT specifies that pneumonia:

Is-a disease of the lower respiratory tract

Finding_site lung structure

Onset (subacute, acute, insidious, sudden)

Severity (mild, moderate, severe)

Episodicity (first, new, ongoing, other)

Course (acute, acute diffuse, acute-on-chronic, etc.).

Similarly, SNOMED CT specifies that Klebsiella pneumoniae:

Is_a Klebsiella

    Is_a enterobacteriaceae

        Is_a gram-negative bacillus

            Is_a gram-negative bacterium

        Is_a bacterium

            Is_a infectious agent

                Is_a microorganism

The linkage concept "due_to" specifies the relationship between the two concepts of "pneumonia" and "Klebsiella pneumoniae." More complex expressions are possible, and can be con-

structed at the point of care, reflecting the clinically relevant data. Encoding of patient information is then accomplished through the post-coordination of the terms "pneumonia" "due to" and "Klebsiella pneumoniae", using a formalism such as description logics that function somewhat as an assembly language for expressing phrases (6).

In this example, the goal is that in well-designed and standardized PMRI systems, all lab reports indicating the type of pneumonia would be located within a standard document architecture, a standard coding scheme would be used to name the pneumonia, and a message could be sent from the PMRI to a reporting document such as the MDS indicating the presence of pneumonia. With respect to pneumonia, the MDS only requires data on the presence or absence of pneumonia. That information could be "messaged" from the PMRI and the MDS form could be sent only with information indicating pneumonia, excluding information on the biological agent that caused the pneumonia. However it is important to retain more detail in automated patient records in order to construct decision support systems that might, for example, suggest cost-effective antibiotics for specific types of pneumonia, detect any possible drug-drug interactions, or enable the reporting of another type of pneumonia, e.g., "pneumonia in anthrax" to appropriate public health agencies.

The relationship of messaging standards, document architecture, and coded terminology systems and formalisms is equivalent to thinking about the grammar that enables us to put words together in order to communicate ideas. Achieving the vision of the NHII requires finding the relevant data within a source document (most easily achieved by creating documents in a structured fashion), composing expressions that include varying degrees of detail, and then "populating" the data fields of an HL7 version 3 message format for transmission to another application. Uniform data structures and encoding are required to accomplish this. All participants, from vendors supplying the software to providers to the government agencies providing oversight of quality, public health, and health policy, must adopt uniform data standards if the data are to be

interoperable, or exchanged across applications and systems. The goal is similar to the use of an ATM card to deposit and withdraw cash at locations remote from one's bank; a major difference is that we all agree on the naming and value of monetary units while we don't agree on how to name our clinical data, or how to formally represent those data.

To date, the NCVHS has not recommended standards around terminology systems. However, desirable characteristics of formal terminologies are well described in the literature and are briefly summarized below (7, 8, 9).

Concept orientation: Tools that empower users to adapt "local terms" to reference terminologies are required when the concepts the terms represent are equivalent. For example, "pressure sores" may be the locally preferred term while "pressure ulcers" is the term in the reference terminology. Therefore well-formed terminologies must accommodate both synonymy and lexical variants, and a thesaurus must be available for automated identification of terms associated with concepts. A promising way to accomplish this is by assembling components into a dynamic terminology server, rather than presenting users with a laundry list of all possible terms.

Comprehensive and complete: Well-formed terminologies must provide the depth and breadth of content coverage relevant to specific domains. This means there must be a way to express all the clinical content required for a wide range of specified uses.

Atomic and compositional: Well-formed terminologies must ensure that "atomic" levels of data are available and that the meaning of atomic level data elements is preserved when combined or post-coordinated with other concepts. A closely related requirement is that concepts are organized within the framework of a reference terminology system that enables the assembly of atomic concepts into more complex expressions (as in the earlier pneumonia example).

Explicit formalism (e.g., description logic): Well-formed terminologies must have a formal logic or inference engine that enables the post-coordination of more complex expressions from atomic level data elements. Presently, description logics appear best suited to this task.

Multiple classifications: In order to support the reuse of clinical data across multiple special purpose classification systems, terminologies must enable concepts to be mapped to multiple "parents". For example, one MDS data element is "short-term memory," and the most similar SNOMED CT term is "uncompensated short term memory deficit." The short-term memory item in the MDS indicates that the patient "seems/appears to recall after 5 minutes." If using the SNOMED CT system for encoding data, one would need to decide which of the following parent classifications represents the intended use of the data.

"Uncompensated short term memory deficit" is classified in SNOMED CT as

    Is_a

        finding of memory performance

            memory finding

                functional finding

                    clinical history and observation finding

                        finding

                            SNOMED CT concept

"Uncompensated short term memory deficit" is also classified in SNOMED CT as

    Interprets

        short-term memory performance

            verbal short-term memory performance

                ability to recall random address at five minutes

                    ability to recall five digit number at five minutes

                        visual short-term memory performance

                            ability to reproduce geometric figure at five minutes

Representation of context. Some experts in the field of electronic medical records believe that well-formed terminologies must be coordinated with structural models of clinical documents within the electronic record in order to disambiguate meaning from use (http://www.hl7.de/cda2002). For example, "History of heart disease" means something very different when recorded in a family history section of the record than when recorded in a past medical history section of the record.

Clearly, the needs for health care data and information reflect multiple and complex uses of that information, and the requirements for terminology systems are extensive. Without terminology standards that support the composition and de-composition of clinically relevant and detailed expressions, interoperability and reuse of patient data across applications and systems will be seriously constrained. Formal terminology coding systems are critical to the success of uniform coding in PMRI systems and to support the evolution of the NHII. This study focuses on three coding systems. Only SNOMED CT has been developed with the specific purpose of meeting the requirements of a reference terminology for PMRI systems. The other two coding systems, ICF and ICNP, are included because they are believed to include many of the definitions and classifications of terms in two subject areas that are particularly relevant to long-term care (functioning, disability and health; and nursing).

SNOMED CT

The Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT) is one of the most extensive terminology systems available. Its development represents collaboration between the College of American Pathologists (CAP) and the United Kingdom's National Health Services. The development of SNOMED CT can be been traced back to 1928 when the New York Academy of Medicine convened a forum to develop a new model for representing diseases and procedures (10). That multi-axial system eventually became the Standard Nomenclature of Diseases and Operations (SNDO) and provided the foundation for modern clinical terminologies. A con-

sistent goal of all subsequent developers of the SNOMED works has been a terminology that is comprehensive enough for indexing the entire medical record.

SNOMED CT is structured in a way that emphasizes a computer readable format. A description logic based formalism supports navigation throughout the multiple hierarchies and allows for the composition of atomic level terms into more complex terms. The most recent version, SNOMED CT July 2002 Release, was used in this study and includes 330,000 concepts, 850,000 synonyms, and 50,000 semantic or defining relationships, for a total of over 1,000,000 terms. This terminology coding system is specifically designed to be embedded or enabled within computer based systems; a browser enables human navigation of the SNOMED CT hierarchies (www.snomed.org).

SNOMED CT was included in this study because it is a formal terminology and has the potential to serve as a convergent or reference terminology. The core data structure in which SNOMED CT is distributed includes a concepts table, a descriptions table, and a relationships table. SNOMED CT is available for use through an annual, renewable license and is distributed in a variety of electronic formats. There are ongoing discussions concerning between the federal government and CAP, that if ratified, would make SNOMED CT generally available for health care use in the U.S.

ICF

The International Classification of Functioning, Disability, and Health (ICF) is an example of a terminology coding system developed to meet a specific need. ICF is one of the families of classifications developed and maintained by the World Health Organization (http://www.who.int). The aims of the developers of the ICF were to provide a scientific basis for understanding the distribution and determinants of health and health-related states; establish a common language in order to improve communication among users of such data; permit comparisons on functioning,

disability, and health across countries, providers, settings, and programs, and provide a coding scheme for health information systems (11). ICF was included in this study because of its emphasis on functional status (an important concept at least in long-term care) and the potential applicability of this terminology to persons in nursing homes.

An example of how ICF codes might be used follows. The ICF code "d4500" refers to "walking short distances." A performance qualifier can be added to this code by adding a fifth digit to the code. For example, "d4500.3" refers to "moderate restriction in performance of walking short distances." A capacity qualifier could be added to this code by adding a sixth digit; for example "d4500._3" refers to "severe capacity limitation in walking short distances."

The ICF is structured around a hierarchical classification of the domain of functioning, disability and health, grouping concepts and associated terms within the domain according to common characteristics or attributes. At the highest level are two broad classes, functioning and disability, and contextual factors. These two broad classes subsume other lower level classes. Qualifiers indicate the magnitude and/or direction of change in body function and structure, capacity and performance estimates related to activities and participation, and facilitators or barriers related to environmental factors. Users may combine terms across axes in order to create profiles of an individual's functioning. While coding rules are published, there is no formal logic available to support such compositions.

In July 2001 the NCVHS reported to the Secretary of Health and Human Services on uniform coding for functional status (12). NCVHS noted that while functional status information is recognized as essential for fostering the goals of healthy people and healthy populations, such information is often missing from clinical notes. The Committee further recommended the use of a uniform code set and classification system for concepts within the domain of functional status. The NCHS said that an internationally agreed upon classification and coding system was needed

to support health care decision making, and that the ICF was the only viable code set presently available. However, the Committee also noted that intense work is needed to examine issues related to the ICF's adequacy, reliability, and validity before any recommendations are adopted about its widespread implementation in PMRI systems. Presently, the ICF is distributed as a book or CD, and a browser is available on the web (http://www3.who.int/icf/onlinebrowser/icf.cfm). The WHO made an electronic copy of the ICF table available for this study.

ICNP

The International Council of Nurses developed the International Classification of Nursing Practice (ICNP) as a way to facilitate the cross mapping of terms and existing nursing vocabularies and classifications such as those recognized by the American Nurses Association (http://www.nursingworld.org). The ICNP was included in this study because of its focus on nursing care, an emphasis clearly related to the issue of quality in nursing homes.

Structurally, the ICNP exists as two multiaxial systems (13). At the highest level are the three classes of phenomena, actions, and outcomes. The axes associated with the phenomena class are focus, judgment, frequency, duration, topology, body site, likelihood, and bearer. By combining terms from these axes, statements can be composed that reflect the aspect of health (or problem/ diagnosis) that is relevant to the nursing care provided. The outcomes class is a serial measure of these same phenomena statements, i.e. outcomes representing changes in phenomena over time. The actions class includes the axes of action type, target, means, time, topology, location, routes, and beneficiary. In a similar fashion, the goal is to compose statements that reflect actions taken by nurses in response to the problem/diagnosis statements composed. As a result of this structure, the ICNP could potentially support aggregation into higher-level categories for summarization, review, research, or administration. However as with ICF, there is no formal logic system by which to accomplish this. As an example, "1A.1.1.2.2.1.1.8.9.2" refers to a nursing focus of

"walking," and a judgment of "1B.7.1.3" refers to "compromised to a high degree." A more complex expression can be post-coordinated by combining "walking" and "compromised to a high degree."

Across the multiple axes of the ICNP there is a somewhat uneven granularity of concepts. Most problematic from a computational perspective is that while some classes have clear hierarchical relationships among the terms in the axes, terms in other classes are arranged alphabetically. This is not problematic for human reading, but does create challenges for machine processing of the system. The ICNP is distributed as a book or CD, and a browser is available free of charge on the Web (www.icn.ch). Spreadsheets containing the ICNP axes were made available by the ICNP for this study.

Federal Support of Terminologies – Consolidated Health Informatics Initiative

Given the federal government's role in providing and paying for health care, the standards used by the federal government can significantly influence decisions on the standards used by health care providers and vendors. The Office of Management and Budget (OMB) identified the Consolidated Health Informatics (CHI) initiative as one of the 24 electronic government initiatives supporting the President's Management Agenda (http://www.jrfii.com/chi). To accelerate the adoption and use of information standards and technology, the CHI will endorse, for future use in federal healthcare programs (i.e., HHS, VA, and DoD), clinical vocabularies and messaging standards that have widespread support and use within the private US health care community. The commitment of federal programs to use agreed upon clinical vocabularies and messaging standards will enable federal agencies to build interoperable federal health data systems, and will encourage the private sector to adopt electronic health information systems that will be compatible with those that federal government will employ, and vice versa. This federal leadership will help inform the private healthcare community's investment decisions in electronic health information systems.

In March 2003, the Departments of HHS, Defense, and Veterans Affairs announced the first set of uniform standards for electronic exchange of clinical health information to be adopted across the federal government. As part of new systems developments, these Departments will adopt HL7 messaging standards, laboratory terminology standards (LOINC), digital imaging standards (DIACOM), and other standards.

The MDS: An Example of a Legacy Coding System

Assessment tools such as the MDS meet predefined needs for data and information. Additionally, these data sets reflect the limitations of the technology that was available when the assessment form was first developed; data storage was far more expensive than it is today, databases were largely limited to "flat files" and the internet did not exist. Typically, forms with specific questions and phrases that reflect the end-users' need for data provide the structure by which persons record values that populate specific fields within the data set. In this approach to data entry, standardized terms, phrases, and sentences are presented in a highly structured format in order to encode concepts related to functioning and disability, thereby enabling consistent and comparable data. The recording of data is accomplished by people who complete the forms on paper and then enter the data into an electronic format, or by completing an electronic version of the form. Often the form provides a structure for organizing clinical data elements into categories that are later aggregated even further in order to meet the goals of various statistical classification and reporting requirements. The important point is that the person completing the form is presented with a limited set of terms and values and must understand the underlying purposes for which the data set was constructed in order to correctly complete the form. The amount and nature of information available for sharing and re-use for purposes such as automated alerts, decision support, quality monitoring, outcomes research and policy development is constrained by the limited scope of the data set.

In addition to the MDS, the Centers for Medicare and Medicaid Services (CMS) provides oversight of two other data sets that focus on the provision of post acute care services: the Outcome and Assessment Information Set (OASIS) for home care agencies, and the Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF PAI) for rehabilitation units and hospitals. Each of these data sets was developed independently of the other. Consequently, different terms are used to describe similar clinical characteristics of beneficiaries, different rating scales are used, and the time periods in which assessments are completed differs, all limiting the comparability of the data. For example, the MDS requires that a value of 0-3 be entered into each of five data fields indicating over the course of seven days the frequency with which a resident exhibits a variety of behaviors classified as "behavioral symptoms". One item concerns each of the following: wandering, verbally abusive behavior symptoms, physically abusive behavioral symptoms, socially inappropriate/disruptive behaviors, and resists care. Behavioral symptoms are further classified as "Mood and behavior patterns." The OASIS-B1 home care data set requires that a single item be checked indicating, over the course of one month, the "Frequency of behavior problems (e.g. wandering episodes, self abuse, verbal disruption, physical aggression, etc.)." These behavioral problems are further classified as "Neuro/emotional/behavioral status." The developers of both data sets were likely interested in the same clinical data. If specific and detailed clinical descriptions were recorded and indexed within the patient's medical record using standardized and uniform data standards, clinically relevant data could be and retrieved and aggregated for reporting requirements. The present situation seriously limits an analysis of the variation in patients and patient outcomes across post acute cares settings, and resulting in insufficient information on which to base policy decisions (14).

This situation is not specific to post-acute care. The data sets on which most public health statistical reporting systems are based were similarly developed independent of each other, and are described as "a patchwork of data collection systems" (15). Among the goals of the NHII is that

reporting requirements could be *derived from* patient medical record information, and given well-coordinated systems consistent and comparable expressions of clinical data would be enabled.

Summary

In summary, achieving the vision of the NHII put forward by the NCVHS requires a high level of coordination among messaging standards, clinical document architecture standards, and standards for terminology coding systems. It is terminologies that provide the content that must be included in messages in electronic health information systems. Although no terminology standards have yet been recommended by NCVHS or the CHI, the characteristics of terminologies that will enable interoperability in electronic patient record systems are well described.

Part Two: The Minimum Data Set for Nursing Facilities

The following section briefly describes the development and multiple uses of the federally required patient assessment form – the Minimum Data Set (MDS) for Medicare and Medicaid certified nursing facilities (NFs). The uses addressed include assessment and care planning, payment, quality indicators, and quality measures. In addition, this section provides a short description of how the MDS is completed and concerns about MDS data accuracy. This section concludes with a brief summary of these issues and a discussion of how refinement of this patient assessment instrument could facilitate more efficient and accurate patient assessment data collection, support the implementation of electronic medical records and information systems in nursing homes, and further the evolution of the NHII.

Assessment and Care Planning

The quality of long-term care has long been a concern among consumers, providers of care, policy makers, and payers. In 1986 the Institute of Medicine (IOM) issued a study entitled, "Improving the Quality of Care in Nursing Homes" (16). The focus of the study was to examine ways to improve the regulation of nursing homes to improve quality of care. A core theme that emerged from that study was the need to standardize assessment and care planning for nursing home residents.

Congress subsequently passed a law in 1987 that required the development of the MDS to ensure that each nursing home resident receives, at regular specified intervals, a comprehensive assessment and care plan designed to meet his/her needs. CMS (formerly known as the Health Care Financing Administration (HCFA)) developed the MDS based on input from various disciplines. The MDS assessment includes more than 583 items that are used by facilities in performing comprehensive assessments of their residents. Thirteen domain areas are included in the MDS

assessment: past medical history and medically defined conditions, medical status, functional status, physical and sensory impairments, nutritional status, special treatments or procedures, psychosocial status, discharge potential, dental condition, activities potential, rehabilitation potential, cognition, and drug therapy (17).

Nationwide electronic collection of the MDS began in the 1990s. As required by statute for assessment and care planning, the MDS is required to be completed shortly after admission, annually, and quarterly thereafter. It is also required upon a significant change in the resident's condition. In most states, a shorter form is used for quarterly assessments than for the more comprehensive admission and annual assessments.

Payment

The MDS is also used in establishing Medicare skilled nursing facility (SNF) payment rates. Beginning in 1998, CMS began paying Medicare SNFs prospective payment rates adjusted using data from the MDS. CMS permits the use of yet another MDS form in calculating Medicare PPS payment rates. The MDS payment form is required to be completed at multiple points during a Medicare SNF stay. In addition, a number of States also use an MDS form to adjust Medicaid nursing facility payment rates.

Quality Indicators and Quality Measures

The NF quality is recognized as affecting a myriad of clinical outcomes that encompass functional, psychosocial and other aspects of resident health and well-being. In 2001 the IOM again published a report on the quality of long term care, emphasizing that "defining or evaluating quality of long-term care is fraught with problems, made more difficult by the unevenness of the available empirical evidence.… Opinions about what constitutes excellent, good, or poor quality also are changing and sometimes conflicting. Some of the available information is open to interpretation,

and conclusions are sometimes based on personal and clinical experience rather than on empiri-cal evidence (18)."

Beginning in 1999, CMS began to use MDS data elements for the creation of "quality indicators" (QIs). These QIs are used in the nursing home survey process to indicate areas of potential qual-ity problems which trigger more intensive review during a survey. A subset of these QIs are published on the CMS Nursing Home Compare Website as a source of public information about nursing home quality (http://www.medicare.gov/NHCompare/Home.asp). CMS believes that the quality indicators have been sufficiently validated to qualify as true measures of quality, al-though others question their validity (19). There has never been any published research on the relationship (validity) of these quality indicators to actual nursing home quality. A study of the validity of the more recently developed quality measures was completed (see discussion below). Although conceptually similar, the numerators and denominators within the ratios and the risk adjustments are constructed differently across the quality indicators and measures.

More recently, CMS embarked on an effort to develop "quality measures" (QMs) that could be used nationally to provide consumers with information about nursing home quality that would assist in their decision making process about nursing home placement. In an April 24, 2002 press release, Health and Human Services Secretary Tommy Thompson said, "A key step to-wards improving quality is getting consumers the information they need to make informed health care choices.… By generating and publishing quality data, we are both helping consumers to make decisions that best meet their needs and creating market incentives for nursing homes to further improve quality" (20).

CMS hired the National Quality Forum (NQF) to select, through a consensus process, measures of nursing home quality using MDS data elements. However, the NQF was unable to reach a consensus about which quality measures could be used in a national reporting effort and there-

fore delayed endorsing a nursing home measurement set. NQF members on various NQF councils were unable to approve all nursing home quality measures, particularly noting the need to review evidence of the validity of the proposed risk adjustment methods (21).

Based on results from a study on the validity of nursing home quality measures, CMS determined that there was in fact sufficient information to select the new quality measures (derived from MDS data) and that those QMs that would be used in national reporting beginning in November 2002. Under contract to CMS, Abt Associates produced a report that, among other things, examined the inter-assessor agreement (a measure of reliability) (22). The study found that all but one of the quality measures was reliable (i.e., a weighted kappa statistic value of .40 or higher).

Controversy surrounds even the new quality measures; in particular there continues to be considerable criticism about the adequacy of the risk-adjustment of these new measures and whether a more rigorous validation study would find relationships between these measures and actual nursing home quality. For example, one of three risk-adjustment experts consulted by the NQF to provide recommendations to CMS about the use of the quality measures as a source of consumer information concluded that "...it would be irresponsible to report any of these quality indicators to the public" because there is insufficient information "that these risk-adjusted quality indicators accurately identify facilities with quality of care problems" (23). Similarly, the GAO recently concluded "although public reporting of quality indicators is a worthwhile goal, it is important for CMS to await and consider input … to identify and evaluate appropriate quality indicators" (24).

CMS responded, noting their intent to develop more refined measures: "As the process of choosing nursing home measures evolved, it became clear that the NQF needs adequate time to fully consider and discuss the Validation Report and to take into account any lessons learned from the

Six-State Pilot Study. Once the NQF reaches consensus and delivers its recommendations, we expect to move to a timely implementation of the updated measures on Nursing Home Compare" (25).

Clearly, significant challenges exist in providing useful and accurate information about quality in long- term care. Failure to reach agreement on a set of quality measures in nursing homes high-lights one of the challenges in measuring nursing home quality. Nursing home quality is a multi-faceted concept. The continued use of the "QIs" in the survey process and as a source of con-sumer information on the Nursing Home Compare website and the "QMs" as another type of consumer information and the mechanism to identify nursing homes in need of quality improve-ment underscores the uncertainty about how to measure nursing home quality. The number of QIs and QMs reflect a number of care domains that are of interest to different stakeholders. In addition, many believe that quality of life is at least equally important in understanding the qual-ity of nursing home care (26), but are included in either the QIs or QMs.

MDS Completion

Presently, nursing facilities do not typically use electronic medical records or robust electronic health information systems. To complete the MDS, NF staff abstract data from medical records, talk with staff, and observe nursing home residents to gather information required for the MDS. NF staff typically record this information on a paper record and at a later time electronically en-code and transmit this information to State and Federal Governments. Abt Associates found that "MDS coordinators who complete each MDS independently were often not at all involved in resident care, and did not work as part of an interdisciplinary team with caregivers to fill out the MDS" and that nursing home providers describe the MDS as "an excessive paperwork burden.... and a time-consuming task that is difficult to manage in the face of inadequate staffing levels and high turn-over rates" (27).

MDS Accuracy

Several studies have identified serious accuracy problems with MDS data. The methods by which inaccuracies were determined varied across these studies but generally included either a review of whether medical record documentation contained information that supported the MDS findings and/or a comparison the nursing home's MDS assessments with those completed by highly trained nurses. The Abt MDS Accuracy Study reported that MDS error rates average 11.6 percent for all MDS items (27). That study reported the least accurate sections of the MDS included cognitive patterns (Section B), psychosocial well being (Section F), physical functioning (Section G), skin condition (Section M), and activity pursuit patterns (Section N). The study also noted problems with under-reporting in the areas of: vision, health conditions, pain, and falls; and over-reporting problems in the areas of: IV medication, intake and output, and physical, occupational and speech therapies. These areas of greatest disagreement generally require substantial periods of observation as well as resident or family interview in order to accurately assess.

Similarly, a study conducted by the Office of the Inspector General (OIG) of the MDS assessments completed for 640 nursing home residents, found errors on 17 percent of the MDS data elements (i.e., 17 percent of the MDS data elements were not supported by information in the medical record) (28).

In a study on nursing home resident assessment, the GAO reported that 9 of the 11 States that had MDS accuracy review programs found MDS errors occurring most frequently in the following categories: mood and behaviors, nursing rehabilitation and restorative care, activities of daily living, therapy, physician visits or orders, toileting plans, and skin conditions (29).

The MDS in Relation to the NHII

There are few indications that the evolution of federally required documents such as the MDS is being discussed in the context of a national health information infrastructure development. As

observed by the IOM in its report entitled, *Leadership by Example: Coordinating Government Roles in Improving Health Care Quality*, "Growing evidence supports the conclusion that automated clinical information and decision support systems are critical to addressing the nation's health care quality gap…. Although it may be possible in the short run … to rely on medical record abstraction … greater computerization of clinical information will be required over the long run to sustain performance measurement, apply it to a broader range of conditions, and decrease the associated administrative burden on providers" (30).

Summary

In summary, the MDS is a paper and pencil assessment form that summarizes data from a variety of sources, may be completed by person who are not knowledgeable about the resident, and is eventually encoded and transmitted electronically to State and Federal governments. MDS forms are used for a variety of purposes:

- Comprehensive assessment and care planning;

- Medicare, and, in some States, Medicaid payments;

- Construction of quality indicators used in the survey process and as a source of public information; and

- Construction of quality measures used as a source of public information.

MDS data inaccuracies can have implications for accurately assessing nursing home residents' needs and developing appropriate care plans, paying appropriate Medicare and Medicaid nursing home payment rates, adequately and appropriately monitoring quality of care, and reporting useful and accurate information about nursing home quality. Deriving administrative data requirements from clinically relevant information collected and recorded at the point of care would significantly reduce the burden providers presently experience in completing the MDS and likely improve the accuracy of data needed to support administrative requirements (e.g., payment, quality monitoring, and public reporting requirements). Most importantly, introducing electronic

medical records and information systems to long-term care would support important enhancements to quality of care when automated alerts, decision support can be built into point of care systems. As emphasized earlier, uniform descriptions of clinical data are essential to the success of any such initiative.

Part Three: A Content Coverage Study

This section describes the purpose of the present study; why the conditions of pressure ulcers, pain, and incontinence were selected; identification of terms, terminology coding systems included in the study, and the methods and procedures used.

Purpose of the Study

The study had three objectives: The first objective was to determine, as a pilot activity, whether leading terminology and classification systems provided content coverage to support clinical decision-making and quality of care oversight in nursing homes as recommended by clinical experts and as reflected in the literature for three domains: pressure ulcers, chronic pain, and urinary incontinence. The second objective was to examine the content of the federally required nursing home minimum data set (MDS) to determine whether it provides the information needed to understand quality of care in nursing homes in the three selected domains. The third objective was to examine the extent to which the content of the MDS was captured by SNOMED CT, ICF, or ICNP.

Specifically, we set out to:
- Identify the concepts, terms, and data elements recommended by domain experts as needed for risk adjusted assessments of pressure ulcers, pain, and urinary incontinence in nursing homes;
- Determine the content coverage needed for these assessments provided by: (i) three terminology coding systems: SNOMED CT, ICF, and ICNP; and (ii) the MDS;
- Determine the extent to which the data elements of MDS are captured by SNOMED CT, ICF and ICNP.

This project was deliberately limited in scope to three clinical conditions in order to provide a focused, "pilot" study that examines the comprehensiveness of leading terminology code sets and the MDS with respect to clinically relevant data and concepts needed to measure quality for those three clinical conditions.

Selection of Study Focus Areas

The three conditions on which the study focused were selected because these conditions are frequently used in constructing measures of nursing home quality. However, quality measures for each of these conditions presents a slightly different documentation challenge that relates to whether the condition is directly observable or not, the type of clinical data required, and the number of persons involved in recording relevant data in the record. The rationale for selecting these three conditions was, in part, based on the following:

Pressure Ulcers and Pressure Ulcer Risk

Pressure ulcers are areas of tissue damage or necrosis that develop due to pressure over a bony prominence; the reported incidence rate for pressure ulcers in long term care facilities varies from 0% to 31% (31). Severe pressure sores are a major source of morbidity and mortality in nursing home residents (including pain, infection, disfigurement, and interference with activities of daily living) (18). The estimated costs of treating a pressure ulcer range from $4000 to $40,000 for newly developed ulcers. A specific goal of Healthy People 2010 is to reduce the prevalence of pressure ulcers in nursing homes by 50% (32).

Because pressure ulcers are directly observable, the documentation of pressure ulcers is relatively straightforward. Additionally, risk factors for the development of pressure ulcers are well described. Therefore, determination of quality of care based on pressure ulcer data can be re-

lated not just to the outcome of pressure ulcer development, but also to processes of care that are known to reduce the risk of pressure ulcer development.

Chronic Pain

Chronic pain is defined in a national clinical practice guideline as "unpleasant sensory or emotional experience that is persistent or recurrent" (33). Estimates of the prevalence of chronic pain in long term care facilities range from 45 to 80%, but these rates are generally considered to be underestimates. In addition to the suffering associated with pain, untreated pain has been associated with increased occurrences of depression, social isolation, sleep disturbances, gait impairment, and increased use of health services (34). Despite strong evidence that chronic pain can be ameliorated by appropriate use of medications, undiagnosed and untreated pain has been a widespread problem in nursing homes.

In part because of the highly subjective nature of chronic pain, assessment and subsequently documentation of an individual's pain can be challenging. While self-report of pain is a "gold standard," persons who are unable to provide an accurate self-report because of conditions such as cognitive or communication limitations are dependent on staff's accurate interpretation of the non-verbal indicators of chronic pain (e.g., facial expressions such as grimacing and frowning, vocalizations such as yelling, groaning, moaning, or behaviors such as bracing, rubbing, and guarding) (18, 34). Documentation of nonspecific signs and symptoms that may suggest the presence of chronic pain is necessary.

Urinary Incontinence

Urinary incontinence is defined as the involuntary loss of urine significant enough to be considered a problem (35). Estimates are that 50% or more of persons in long-term care facilities are affected by incontinence, reflecting the role of incontinence as a cause of institutionalization.

Incontinence is associated with skin breakdown, activity limitation, social isolation, and depression (36). Because incontinence can be reversed or improved for up to half of nursing home residents, a high prevalence of incontinence suggests poor care (18).

Because of the types of evaluations required in determining the cause of incontinence, relevant documentation is typically found in many different sections of clinical records (e.g., history and physical, nursing notes, laboratory reports), and those data are typically recorded by persons in a variety of health care disciplines.

Identification of Terms

Our primary goal was to examine the content coverage provided by select terminologies and the MDS for measuring quality of nursing home care with respect to the three selected conditions identified above. The study used the following methods to generate a list of relevant terms that served as the test set for examining the content coverage provided by three different coding systems.

ACOVE Indicators

First, the project team retrieved quality indicator data from recently published synthesis conferences on quality indicators for each of the selected conditions. A Task Force on Aging with members from the American College of Physicians and the American Society of Internal Medicine recently published a set of manuscripts concerning the assessment of quality of care for older persons, a project entitled "Assessing Care of Vulnerable Elders" (ACOVE) (37). Among the goals of the project was to develop a set of evidence-based, quality of care indicators relevant to vulnerable older persons, and to design a chart abstraction tool, interview instruments, and data analytic methods to implement a quality-of-care indicator system. Three of the manuscripts specifically addressed quality indicators for the domains of pain management, pressure ulcers,

and urinary incontinence (32,34,36). Efforts that summarize the essential literature in specific areas, like the ACOVE initiative, are important for terminology work because they represent consensus among experts in the field on the key terms and concepts relevant to the knowledge base required for specific domains.

Although the ACOVE project focused on the identification of high-risk, community dwelling older persons, we chose to include the data elements put forward in these manuscripts for several reasons. First and most important for our purposes, there was a deliberate effort to develop the quality indicators considering information typically available in the medical record and administrative data. Second, each focused area included aspects of prevention, diagnosis, treatment and follow-up. Finally, the indicators were specifically developed for use in assessing the processes of care delivered to vulnerable older persons. See Appendix A for a listing of the ACOVE indicators for each of the three clinical conditions included in this study.

Domain Experts

Second, the project team identified one content expert for each domain based on their authorship of key citations retrieved from the literature review. The experts were asked to provide a listing of key literature related to their area of expertise, and of key clinical data they believed essential to making judgments of quality of care related to their specific area. This was felt to be necessary because literature synthesis by definition requires that content be summarized; and rarely includes a full complement of terms that are potentially relevant to any given focus area. In particular, we were interested in the types of clinical documentation terms that these reviewers identified.

Pressure Ulcers and Pressure Ulcer Risk: Nancy Bergstrom, Ph.D., RN, FAAN, is the Associate Director of Aging Research the Center on Aging at the University of Texas Health Sciences Center. Dr. Bergstrom was the chair of the AHCPR panel that developed the clinical practice

guidelines for the prediction and prevention of pressure ulcers in adults. She has published numerous journal articles related to the assessment and treatment of pressure sore risk for nursing home residents and was the Principal Investigator for the 1988-1994 NIH study "Nursing Assessment of Pressure Sore Risk."

Chronic Pain: Keela Herr, Ph.D., R.N. is Professor and Area Chair: Adult and Gerontology Nursing at the University of Iowa. The primary focus of her work and expertise is in the area of pain assessment in older adults. She has conducted NIH funded research to establish appropriate tools for evaluating pain intensity among the elderly population. She is currently working on the AHRQ sponsored research project, "Evidence-based Practice: From Book to Bedside: Acute Pain Management in the Elderly" that is examining interventions to improve adoption of clinical practice guidelines in health care organizations.

Urinary Incontinence: John F. Schnelle, Ph.D. is the Director of the Boren Center for Gerontologic Research at the UCLA/Jewish Home for the Aging. He has been the principal investigator on nine NIH clinical trial intervention grants designed to improve care and management in nursing homes. Dr. Schnelle has published numerous journal articles related to the assessment and treatment of urinary incontinence among nursing home residents and was part of the AHCPR panel that developed the clinical practice guidelines for urinary incontinence. He is the author of the 1991 book "Managing Urinary Incontinence in the Elderly."

The domain experts were asked, based on their expertise, to:

- Identify and refine the key terms and concepts needed to understand quality in their domain (i.e. data elements).
- Specify the quality inferences (and the data source(s)) that could be supported if all relevant data were available.

- Identify the data elements (and corresponding data source(s)) needed to risk adjust these estimates of quality.

- Provide a list of references related to their domain area.

Appendix B includes a list of the terms provided by each of the domain experts, and Appendix G a list of key literature citations provided by the domain experts.

Quality Indicators and Quality Measures

Third, a list of the MDS data elements associated with the quality indicators and quality measures was compiled. Quality <u>indicators</u> derived from MDS data were described earlier in this paper. The pressure ulcer quality indicator is "Prevalence of stage 1-4 pressure ulcers" and is derived from the single MDS data element "pressure ulcer – any lesion caused by pressure resulting in damage of underlying tissue." Two quality indicators are relevant to incontinence: "Prevalence of bladder or bowel incontinence" and "Prevalence of occasional or frequent bladder or bowel incontinence with or without a toileting plan." The respective MDS data element is "Control of urinary bladder function or continence programs, if employed." This data element is then coded according to whether the individual is usually continent, occasionally incontinent, frequently incontinent, or incontinent all of the time. Appendix C includes examples of data from the MDS used to derive quality indicators related to pressure ulcers and incontinence. There is not a quality indicator for chronic pain.

The nursing home quality <u>measures</u> are derived from MDS data elements, as are the quality indicators. The quality measures of interest in this study are related to residents with pressure sores and pain. For the measure of prevalence of stage 1-4 pressure ulcers, the MDS data element is the same pressure ulcer data element listed above, with a risk adjustment factor based on the data elements "impaired transfer or bed mobility" or "comatose" or "malnutrition" or "end stage disease." For the measure of inadequate pain management, the MDS data elements include "resi-

dents with moderate pain at least daily" or "horrible/excruciating pain at any frequency." This measure is covaried by the MDS data elements "independence in decision making." Appendix D includes examples of data from the MDS used to derive quality measures related to pressure ulcers and pain.

Terms Abstracted From the MDS

We also examined the content coverage provided by the three coding systems (i.e., SNOMED CT, ICF, and ICNP) for the entire MDS. This was necessary given the emphasis of the domain experts and ACOVE indicators on the identification of a range of factors beyond the occurrence of the pain, pressure ulcers, and urinary incontinence (e.g., risk factors, nonspecific signs and symptoms, and processes of care). That is, the MDS data elements used for QI and QM estimates are a subset of the entire MDS and only concern the presence of these conditions. Since the ACOVE indicators and the domain experts recommend considering factors beyond just the presence of the condition as an indicator of quality, we needed to examine the extent to which: (i) each of the three terminology coding systems provided content coverage of the entire MDS; and (ii) the entire MDS provided content coverage relevant to the ACOVE indicators and domain expert indicators.

This required that we carefully consider the way the structure of the MDS document because interpreting the meaning of specific data elements is tightly coupled to the hierarchy, or headings under which that item occurs in the document.

The MDS is organized into 18 sections, with a varying number of items in each section that specify a focused type of assessment.

Section A: Identification Information, Demographic Information, Customary Routine, and Face Sheet Signatures

Section B: Cognitive Patterns

Section C: Communication/Hearing Patterns

Section D: Vision Patterns

Section E: Mood and Behavior Patterns

Section F: Psychosocial Well-being

Section G: Physical Functioning and Structural Problems

Section H: Incontinence in Last 14 Days

Section I: Disease Diagnoses

Section J: Health Conditions

Section K: Oral/Nutritional Status

Section L: Oral/Dental Status

Section M: Skin Condition

Section N: Activity Pursuit Patterns

Section O: Medications

Section P: Special Treatments and Procedures

Section Q: Discharge Potential and Overall Status

Section R: Assessment Information

The MDS data elements that are actually encoded and stored are selected from pick-lists of responses to a number of items or questions within each of these sections. Many sections of the MDS are further subdivided with sub-headings that organize specific items.

For example, Section G: Physical Functioning and Structural Problems specifies a sub-heading of "bed mobility" which is defined as "how resident moves to and from lying position, turns side to side, and positions body when in bed". The person completing the MDS form then records a value of 0, 1, 2, 3, 4, or 8 to describe the resident's overall self-performance of bed mobility and a value of 0,1,2,3, or 8 to indicate the support provided the resident in bed mobility. To com-

pletely express the meaning of the concepts, it is necessary to consider the text that explains the numeric coded value in association with the item, the sub-heading, and the section heading.

Another example is the concept of "weight change". The term "weight change" is a sub-heading with the section of "oral/nutritional status". A response of No or Yes is required for two separate items within this sub-heading. One item is "weight loss – 5% or more in last 30 days or 10% or more in last 180 days" and the other item is "weight gain – 5% or more in the last 30 days or 10% or more in the last 180 days". In another section of the MDS, "health conditions", there is a sub-heading of "problem conditions", and a list of four items that are "indicators of fluid status". One of those items is "weight gain or loss of 3 or more pounds within a 7 day period". The person completing the form is instructed to check the associated data field if this applies. In the first example, the meaning of the MDS weight change item is related to nutritional status, while in the second example the meaning is related to conditions associated with fluid balance concerns, such as congestive heart failure. The point is that the terms that define the structure of the document contribute to the meaning or semantics of the data elements. These must be made explicit in computer based applications that process the *meaning* of coded data elements. The coded data elements of Yes or No do not carry any meaning related to the intent of the items with which they are associated.

The overall point to be made is that in order to complete a study of the extent to which various terminology systems provide content coverage for the MDS, it was necessary to include all of the terms in items, sub-headings, and sections that provide the context and meaning of a given data elements. Given that an intent of the study was to determine the content coverage of concepts within the MDS, all terms used within the MDS to label section headings, focused areas of assessment, and data elements were included. Duplicates were removed (e.g., "independent" was only included once). This resulted in a sample of 639 unique terms from the MDS. See Appendix F for a complete listing of these terms.

Terminology and Classification Coding Systems

One terminology coding system and two classification systems were included in this study: SNOMED CT (a large, comprehensive terminology system), and ICF and ICNP (small, domain specific classification systems). The systems were previously described, and only summary information is provided below. Investigators obtained electronic copies of each coding system from the developers, as well as permissions to use the coding systems in this project. See Appendix E for contact information for each coding system.

Coding Procedures

Terms from the ACOVE indicators, the domain experts, and the MDS data elements were entered into a spreadsheet, one element per row. As described above, each phrase within the MDS was considered a discrete data element for the purpose of the content coverage study, whether the phrase existed as a section header, item, or response option. Terms were then classified as administrative information, resident history, assessments, treatments, or other (terms referring to provider information, quantities (e.g., 1 to 500 cc/day) and miscellaneous activities) in order to facilitate analysis.

The terminology coding systems were imported into a database within the Mayo terminology services. This set of services is a compendium of tools that facilitate terminology indexing. There are two main divisions within the set of tools, corresponding to the server side and the client side. On the server side, there is a suite of terminology services that contain the core mechanisms for serving up and storing coded content. On the client side, there are graphical building blocks for searching and navigating the hierarchy of underlying terminologies, and for building complex coded expression if supported by the terminology system. Included within the Mayo terminology server is a basic spell checking service, a lexical variant generator (LVG), a syno-

nym scheme, and a coding scheme service. Originally developed to support SNOMED RT, this suite of tools can be modified to accommodate other terminology coding systems.

A trained and experienced coder exhaustively searched for the best available concept or set of concepts that captured the clinical notions expressed by the target phrase from the ACOVE indicators, domain experts, and MDS. If no reasonable match was suggested by the coding tool, she further searched for matching terms from the terminology coding systems using common word processing techniques such as "find" functions. Results are presented in the next section of this paper.

Part Four: Results

This section presents the results of the content coverage study. First, we compare the terms identified by the ACOVE documents, domain experts, and the MDS QI and QM metrics related to quality assessments of chronic pain, pressure ulcers, and urinary incontinence. Then, we summarize the content coverage provided by these terminology systems for the MDS overall.

Comparison of Terms: ACOVE Indicators, Domain Experts, and QIs/QMs

Tables 1, 2, and 3 compare the terms we abstracted from three sources: the ACOVE indicators, the domain experts, and the MDS quality indicators and quality measures. To facilitate comparisons and analyses, we grouped data elements into the broad categories of targeted history and physical, treatments for condition, and assessments. It is important to remember that we asked the domain experts to suggest data elements that would be required to assess quality of care; therefore most of the terms from the domain experts reflect assessments. The relative lack of detail of terms related to treatments should not be interpreted as indicating the expert would not or could not recommend treatments. Our request to the domain experts emphasized a request for data elements that are associated with assessment indicators for each of the specific conditions.

It is striking to note that across these three tables, the number of terms dramatically diminishes as one moves from the domain experts and ACOVE indicators to the MDS data elements. This reflects the limited scope of the MDS, and subsequently the limited data available for making decisions related to the quality of care. The terms provided by the ACOVE indicators and the domain experts reflect the far more extensive data typically recorded (and available) in clinical records.

The difference in the number of terms also reflects an emphasis by the ACOVE documents and the domain experts that quality judgments must be associated with clinical decision-making, in

contrast to summary measures of quality that are reflected in incidence and/or prevalence rates that emphasize counting events. The ACOVE groups and the domain experts emphasized that it is the failure to identify persons who might benefit from related processes of care and to then provide that care that is one of the most significant indicators of poor quality. The MDS quality indicators and measures emphasize the incidence and prevalence of events, i.e., the occurrence of pressure ulcers, pain, and incontinence – not the timely detection and early intervention to prevent those events from occurring.

Given the limited coverage provided by the MDS quality indicators and quality measures for the targeted domains, we felt it was important to also examine the content coverage of the entire MDS in relation to the ACOVE indicators and domain expert terms in order to determine whether the indicators recommended by the ACOVE manuscripts and the domain experts could be derived from MDS data elements. This review is provided below in the section entitled, "Content Coverage for Domain Expert Terms." Unfortunately, even when examining the entire content of the MDS, the MDS does not provide much of the data content recommended by the ACOVE documents or the domain experts.

Table 1.

A Comparison of Recommended Data Elements to Infer Quality of Care for Persons with Pressure Ulcers/At Risk for Pressure Ulcers

	Pressure Ulcers: ACOVE	Pressure Ulcers: Domain Expert	Pressure Ulcers: MDS Quality Measure
Targeted history and physical	Risk assessment	Risk for decreased tissue perfusion: Tobacco use and CABG procedure Radiation treatment History of ulcers History of hospital stays Surgical treatments: Surgical flap At risk for developing pressure ulcers High risk for pressure ulcers Risk assessment tools Braden scale Norton scale Skin inspection Periodic reassessment	
Treatments for condition	Preventive interventions Nutritional interventions Management Debridement Cleansing Topical dressings Management If at risk, then repositioning and pressure reduction for tissue loads If at risk and malnourished, then nutritional intervention	Ulcer care plan Application of dressings Clean dry dressings Dressings that keep ulcer bed continuously moist Protective dressings Cleanse wound Mild cleansing agent Whirlpool treatment Wet to dry dressings Debridement Topical debriding agents Autolytic debridement	

	Pressure Ulcers: ACOVE	Pressure Ulcers: Domain Expert	Pressure Ulcers: MDS Quality Measure
	If ≥ stage 2, no topical antiseptic If full thickness sacral or trochenteric with necrotic debris or eschar, then debride If clean full-thickness or partial-thickness, then topical dressing If s/s of infection with no other cause, then debride within 12 hours, tissue biopsy or needle aspiration for culture and sensitivity within 12 hours	Enzymatic debridement Mechanical debridement Wound irrigation Foam Gel Growth factors Hormones Hyperbaric oxygen Infrared ultraviolet Hydrotherapy Normal saline Topical agents Topical aminoglycoside treatment Topical antibiotics Topical treatment with iodine containing agents Avoid massage over bony prominences Moisturizers Lubricants (corn starch and cream) Electrical stimulation therapy Low energy laser irradiation Assisted oral feeding Oral supplements Devices that totally relieve pressure Distribution of weight Proper postural alignment Characteristics of support surfaces Dynamic support surface Low air loss bed Pressure relief Pressure reducing beds Pressure reducing mattresses Pressure reducing overlays Maintain position in bed or chair Nutritional management Aggressive nutritional interventions Air fluidized beds Plan of nutritional support	

	Pressure Ulcers: ACOVE	Pressure Ulcers: Domain Expert	Pressure Ulcers: MDS Quality Measure
		Patient education Repositioning schedule Surgical flap Postoperative viability of the surgical site Evaluate adequacy of treatment	
Assessments	Risk assessment Evaluation If unable to reposition self, then risk assessment for pressure ulcers If pressure ulcer, assess for location, depth, stage, size, presence of necrotic tissue If partial thickness pressure ulcer and no improvement after 2 weeks then assess appropriateness of tx plan	Age, gender Cognition: Comatose, Cognitive skill, Distracted, Awareness, Restlessness, Lethargy, Mental function, Altered level of consciousness, Depression score, Mental status Speech, Verbal responses Ability to move: Bed mobility, Bed bound, Chair bound, Transfer ability, Walking ability, Locomotion, Dressing ability, Motion of: neck, arm, hand, leg, foot; ADL function, Activities of daily living, Restraint use, Body control, Mobility device, Difficulty with repositioning, Impaired ability to reposition, Immobility, Spinal cord injury, Physical status Nutrition: Eating ability, Nutritional intake, Oral/nutritional status, Oral problems, Oral nutritional supplements, Enteral feeding, Modular products, Vitamin/mineral supplements, Weight loss, BMI, Poor meal intake, Dietary intake, Albumin, Nitrogen balance, Nutritional status, Dietary intake of protein, Dietary intake of calories, Malnutrition, Nutrition screening, Nutritional assessment Risk for moisture exposure: Toilet use, personal hygiene, bathing, bowel	Pressure ulcer *Risk adjustment:* Impaired transfer or bed mobility OR *Risk adjustment:* Comatose Malnutrition End stage disease

	Pressure Ulcers: ACOVE	Pressure Ulcers: Domain Expert	Pressure Ulcers: MDS Quality Measure
		incontinence, bladder incontinence Toilet use, Briefs, Protective padding, Underpads, Skin hydration Recurrence of pressure ulcer Location of pressure ulcer Stage of pressure ulcer Ulcer healing Friction injuries Bed linen to move Lifting devices Minimize force and friction Positioning devices Transferring support Turning techniques Risk for delayed healing Bony prominences Infections	

Table 2.

A Comparison of Recommended Data Elements To Infer Quality of Care for Persons with Chronic Pain

	Chronic Pain Management: ACOVE	**Chronic Pain: Domain Expert**	**Chronic Pain: MDS Quality Measure**
Targeted history and physical	If newly reported chronic pain condition then history and physical within 1 month If treated with NSAIDs, check history of peptic ulcer disease If history of peptic ulcer disease, justify NSAID use If treated with opioids, then bowel regimen/treatment	Presence of diagnoses known to be painful: osteoarthritis, low back pain, fibromyalgia, spinal stenosis, post-herpetic neuralgia, peripheral neuropathy, myofascial pain syndromes, vasogenic claudication, phantom limb pain, headaches, vasculitic pain syndromes, osteoporosis with fractures, cancer, contractures, peripheral vascular disease, rheumatoid arthritis When starts, what started it, what makes it better, what makes it worse	
Treatments for condition	If newly reported chronic pain condition then offer treatment Acetominophen for OA NSAIDs for OA Opioids Avoid meperidine	Pain intensity monitoring Appropriate use of medications Appropriate use of non-pharmacologic interventions Acetominophen for OA NSAIDs for OA Opioids Avoid meperidine	

	Chronic Pain Management: ACOVE	**Chronic Pain: Domain Expert**	**Chronic Pain: MDS Quality Measure**
Assessments	If treated, then assess for response within 6 months Depression Palliative care Side effects of new medications Education concerning medication side effects Osteoarthritis	Dementia Delirium Pain Scales: Numeric estimate (0-100) Verbal descriptors: no pain, moderate, severe, excruciating, worst pain possible, most intense pain imaginable Faces pain scale Pain map McGill pain questionnaire Pain Behaviors: Facial (wrinkled forehead, tightly closed eyes, grimacing, frowning) Nonverbal behavior (bracing, rubbing, guarding) Vocalizations (crying, yelling, groaning, moaning) Nonverbal indicators of discomfort: Aggressive, crying, fearful, negative vocalization, noisy respirations, pacing, repetitive, restlessness, rocking, confusion irritability, increased activity, withdrawal, tense, calling out, grunting, knees pulled up Other changes in usual activities or behavior patterns/routines Impact of pain on quality of life outcomes Physical function, sleep, appetite, interpersonal relationships/interactions with others, mood (anxiety, depression), mental status (ability to think clearly/concentration/confusion), energy/fatigue	Moderate pain at least daily Horrible/excruciating pain at any frequency Independence in decision making

Table 3.

A Comparison of Recommended Data Elements to Infer Quality of Care for Persons with Urinary Incontinence

	Urinary Incontinence: **ACOVE**	**Urinary Incontinence:** **Domain Expert**	**Urinary Incontinence:** **MDS Quality Measure**
Targeted history and physical	If new or persists ≥ 1 month, then targeted hx: Voiding characteristics Ability to get to toilet Previous tx for incontinence Importance of problem to pt. Mental status If new or persists ≥ 1 month, then targeted physical: Rectal exam Genital system exam If new or persists ≥ 1 month, then dipstick ua and post-void residual If newly discovered overflow incontinence and indwelling catheter used, documentation that not candidate for other interventions as result of physical or mental impairments or tx preference	Characteristics of voiding and non-invasive bladder diagnosis Ability to toilet Prior treatment for incontinence Importance of problem to patient Mental status exam Rectal exam to exclude fecal impaction Skin exam to evaluate skin problems associated with urinary incontinence Genital system exam to identify physical abnormalities that may explain incontinence (e.g., pelvic prolapse)	
Treatments for condition	If cognitively intact without hematuria or high post void residual, then behavioral therapy If surgery or periuretheral injections, then cystometry before procedure If female with stress incontinence caused by sphincter deficiency, then	Prompted toileting Prompted voiding Scheduled toileting Timed voiding	

	Urinary Incontinence: ACOVE	Urinary Incontinence: Domain Expert	Urinary Incontinence: MDS Quality Measure
	surgery is sling or artificial sphincter procedure Behavioral therapies		
Assessments		MDS recall scale, MDS item B3, or Cognitive performance scale derived from MDS items Frequency of incontinence Status of incontinence: day and night Symptoms on urination Symptoms to distinguish between urge incontinence (short interval between sensation to void and bladder contraction) and stress incontinence (urine loss during physical movements) Mobility problems on MDS and provider notes Toileting responsiveness assessments: How often person voids when prompted on a routine basis Voiding record Non-invasive diagnoses of bladder function Urodynamic analyses of bladder functioning (for select diagnoses) Lab reports Primary care notes	Control of urinary bladder function or continence programs, if employed *Risk adjustment:* Severe cognitive impairment Totally ADL dependent in mobility Total dependence in ADL self-performance

Content Coverage for Terms Provided by Domain Experts

After generating the lists of terms from the domain experts, we proceeded to code those terms using procedures described earlier. Table 4 compares the content coverage of the MDS and the three coding systems (SNOMED CT, ICF, ICNP) for the terms identified by the domain experts. As expected, SNOMED CT provided the most complete content coverage, consistent with the far more extensive compilation of terms within that terminology coding system. For the domains of chronic pain and urinary incontinence, SNOMED CT provided coverage for all the terms suggested by domain experts and a complete match was possible for the overwhelming majority of terms. For the domain of pressure ulcers, SNOMED CT provided a complete match with 80% coverage observed. The types of terms for which no SNOMED CT code could be identified included abbreviations (e.g., MR/DD, ADL, and a variety of qualifiers such as none of the above). The ICF and ICNP each provided either complete or partial content coverage for approximately half of the domain expert terms related to pressure ulcers and urinary incontinence, but only a small percentage of content coverage for the terms related to chronic pain.

Coverage provided by the MDS varied significantly across domains. The MDS provided a complete match on 70 percent of the pressure ulcer terms, but provided a complete match on only 8 percent of the terms recommended by the domain experts to assess of quality of care relate to pain and urinary incontinence. This is not an unexpected result, and is probably explained in part by the nature of three conditions selected for this review. As noted earlier, pressure ulcers are directly observable and were widely recognized as an issue of concern when the MDS was originally developed. Chronic pain is not directly observable and the presence of chronic pain is either directly reported by the person experiencing the pain or inferred by persons providing care to the person experiencing the pain. In the latter case, a correct inference requires that the provider observe for a wide variety of non-specific behaviors and then correctly interpret those behaviors as pain behaviors. This is the sort of information that should be recorded in clinical

documentation systems (whether paper or electronic). Similarly for urinary incontinence, the results of diagnostic and evaluation tests such as laboratory work and procedure results are typically recorded in clinical documentation systems. The MDS was not developed as a clinical documentation system.

Appendix G includes detailed lists of terms provided by the domain experts that do not have a complete "match" in either MDS or SNOMED CT (i.e., the "partial match" or "no match" columns of Table 4). It will be difficult to achieve the goal of "interoperable" or reusable data across applications without these terms.

For example, if a person has an existing pressure ulcer and is at known risk for the development of additional pressure ulcers, practice guidelines recommend that a skin inspection be completed at least once a day with particular attention to bony prominences and that either static or dynamic support surfaces be used depending on the person's ability to assume a variety of positions without weight bearing. Terms related to the concept of "bony prominences" were not found in either the MDS or SNOMED CT. The MDS includes two items related to pressure relieving devices; one is "pressure relieving devices for chair" and the other, "pressure relieving devices for bed". However our domain expert mentioned five more specific terms related to pressure relieving devices: air-fluidized beds, characteristics of support surfaces, dynamic support surface, low air-loss bed, and static support surface. SNOMED CT does provide terms related to these more specific concepts. The MDS use of the concept appears to be related to whether a pressure relieving device was used in a chair or a bed. More detailed information is needed in order to use the concept in an automated clinical decision support system (i.e., the type of pressure relieving device would need to be made explicit). Persons actually completing point of care clinical documentation would likely provide information at the more detailed level. A reporting interest in whether that device was used for a chair or bed could then be algorithmically derived from the more specific information within an electronic clinical documentation system.

Another example illustrating the need for terminology completeness relates to the names of specific clinical assessment scales. SNOMED CT includes names of many scales used in health care. For example, the McGill Pain Questionnaire and the FACES pain scale are terms within SNOMED CT, however neither the Braden Scale nor the Norton Scale were included in SNOMED CT at the time of this review, nor is pressure ulcer risk quantified in the MDS. Automated clinical alerts when critical values of the Braden Scale or Norton Scale are observed would likely result in the earlier deployment of preventive interventions (such as pressure relieving devices) and therefore a reduction in the incidence of new pressure ulcers. This means that the concept of a Braden Scale score or a Norton Scale score must be available within a given system. The developers of SNOMED CT have a defined procedure for updating the content of this terminology. Researchers at Mayo will submit the terms that were found to not have a complete match in SNOMED CT to the developers of SNOMED for their consideration as terms that should be added to SNOMED.

In the present analysis we included only the specific name of the clinical assessment scale recommended by the domain expert. We did not retrieve specific content within any given scale and further determine the content coverage of that scale. Readers should not automatically assume that because the name of the scale is missing that the content of scale is missing. Researchers at Mayo Clinic are working to apply natural language processing techniques to discover "kernel concepts" in such clinical scales, and will focus future content coverage studies on identifying the terms that may be lacking in clinical terminology systems.

Table 4.
Content Coverage Provided by Selected Coding Systems for Terms Related to Three Domains of Quality:
Chronic Pain, Pressure Ulcers, and Urinary Incontinence

Terms Provided by Domain Experts	MDS Coverage of Terms			SNOMED CT Coverage of Terms			ICF Coverage of Terms			ICNP Coverage of Terms		
	Complete Match[1]	Partial Match[2]	No Match	Complete Match[1]	Partial Match[2]	No Match	Complete Match[1]	Partial Match[2]	No Match	Complete Match[1]	Partial Match[2]	No Match
Pressure Ulcers (n=179 terms)	70%	-----	30%	77%	10%	13%	18%	37%	47%	16%	24%	60%
Administrative Information (n=5 terms)	100%	-----	-----	100%	-----	-----	-----	20%	-----	-----	-----	100%
Resident History (n=10 terms)	80%	-----	20%	80%	-----	20%	-----	10%	90%	20%	40%	40%
Assessments (n=82 terms)	75%	-----	25%	85%	13%	2%	12%	50%	38%	21%	28%	50%
Treatments (n=82 terms)	50%	21%	29%	90%	10%	-----	-----	-----	-----	25%	40%	35%
Chronic Pain (n=79 terms)	8%	8%	84%	92%	8%	-----	4%	9%	87%	3%	5%	96%
Administrative Information												
Resident History (n=19 terms)	26%	16%	58%	94%	5%	-----	-----	26%	73%	5%	10%	84%
Assessments (n=53 terms)	9%	13%	77%	84%	16%	-----	6%	17%	77%	2%	2%	96%
Treatments (n=7 terms)	-----	-----	100%	100%	-----	-----	-----	-----	100%	15%	-----	85%

Terms Provided by Domain Experts	MDS Coverage of Terms			SNOMED CT Coverage of Terms			ICF Coverage of Terms			ICNP Coverage of Terms		
	Complete Match[1]	Partial Match[2]	No Match	Complete Match[1]	Partial Match[2]	No Match	Complete Match[1]	Partial Match[2]	No Match	Complete Match[1]	Partial Match[2]	No Match
Urinary Incontinence (n=28 terms)	8%	8%	84%	95%	5%	-----	4%	50%	46%	4%	46%	50%
Administrative Information												
Resident History (n=2 terms)	-----	-----	100%	100%	-----	-----	-----	50%	50%	-----	50%	50%
Assessments (n=20 terms)	15%	15%	70%	85%	15%	-----	5%	50%	45%	5%	50%	45%
Treatments (n=6 terms)	-----	15%	85%	100%	-----	-----	-----	50%	50%	-----	-----	100%

1. Complete match indicates a lexical match and/or synonyms (e.g. "ability to toilet" and "ability to use toilet")
2. Partial match includes either of the following
   - terms with a broader or narrower conceptual meaning (e.g., the ICF code of "Weight maintenance function" has a broader conceptual meaning than the domain expert term of "weight loss")
   - coverage of some but not all concepts in the target term (e.g., the ICNP code of "nursing home" provides partial coverage of the MDS term "prior stay at this nursing home")

Content Coverage Provided for Terms Within the Minimum Data Set

Table 5 compares the content coverage of SNOMED CT, ICF, and ICNP for all terms within the MDS. Again, as expected SNOMED CT provided the most complete coverage of the three coding systems reviewed in this study.

A few comparisons are of particular interest. First ICNP provided relatively complete coverage of interventions compared to ICF. This is very consistent with the focus of the ICF on providing a profile of functioning and disability, while the emphasis of the ICNP is on interventions provided by nurses as well as patient assessments. Similarly, the content coverage of administrative terms is more extensive in the ICNP than in the ICF.

Table 5.

Content Coverage Provided by Selected Coding Systems for All Terms Within the Minimum
Data Set (MDS)

Terms Within the MDS	SNOMED CT Coverage of Terms		ICF Coverage of Terms		ICNP Coverage of Terms	
	Complete Match[1]	Partial Match[2]	Complete Match[1]	Partial Match[2]	Complete Match[1]	Partial Match[2]
(n=628 terms)	*46%*	*45%*	*2%*	*39%*	*12%*	*50%*
Administrative Information (n=87)	20%	71%	-----	8%	1%	38%
Resident History (n=143)	89%	7%	-----	40%	1%	53%
Assessments (n=262)	29%	66%	4%	58%	20%	53%
Treatments (n=93)	63%	33%	-----	31%	20%	57%
Other[3] (n=43)	40%	37%	-----	7%	2%	38%

1. Complete match indicates a lexical match and/or synonyms (e.g. "ability to toilet" and "ability to use toilet")
2. Partial match includes either of the following
    - terms with a broader or narrower conceptual meaning (e.g., the ICF code of "Weight maintenance function" has a broader conceptual meaning than the domain expert term of "weight loss")
    - coverage of some but not all concepts in the target term (e.g., the ICNP code of "nursing home" provides partial coverage of the MDS term "prior stay at this nursing home")
3. "Other" includes terms such as provider information (e.g., signature), quantities (e.g., 1 to 500 cc/day), and available activities (e.g., cards/other games)

A discussion of these results follows in the next section.

Part Five: Discussion

In this section we first discuss the comparison of data elements on which inferences of quality are based, and the content coverage provided by three different coding systems for those data elements. We then discuss potential implications of this study in relation to continuing initiatives around an information infrastructure of health care.

Essential Data Elements for Inferring Quality

The data elements suggested by the domain experts, ACOVE indicators, and MDS quality measure reflect differing perspectives related to the essential data on which to infer quality of care. There is clearly a different emphasis on the type of information needed to understand quality between the clinical experts (both the individual domain experts and the ACOVE panels) and the MDS quality measures. The clinical experts emphasized assessments that identify persons with actual or potential problems, and then link those assessments and judgments to processes of care. A repeating theme in the ACOVE panels is that it is the failure to identify persons who would benefit from specific care processes that is an indicator of quality, not merely the occurrence of the event.

The focus of the MDS quality indicators and quality measures is on the prevalence of the three conditions, reflecting in part the nature of data within the MDS but also perhaps a public demand for prevalence and outcomes data. However, as experts in the measurement of quality emphasize, such data are extremely difficult to interpret accurately, particularly in the absence of information needed to adequately risk adjust and the absence of information about the processes of care associated with those outcomes. This suggests that the MDS quality measures may not be the most relevant indicators of quality for inferring quality.

The construction of quality indicators and quality measures from MDS data elements is constrained by the availability of data within the MDS; the availability of data within the MDS is constrained by the limited clinical content within the MDS. The difference in the extent to which the MDS provided acceptable pressure ulcer data compared to chronic pain and urinary incontinence data suggests that the MDS be examined carefully for the completeness with which quality inferences can be made. A highly coordinated and structured NHII would enable reporting data for quality oversight functions to be derived from a patient medical record information system. In addition, and perhaps more important to improving quality in long-term care facilities, automated decision support systems could be built within that patient medical record information (PMRI) system thereby providing alerts and reminders at the point-of-care.

Content Coverage Provided by Terminology Coding Systems

The results in the previous section clearly indicate that a large, comprehensive terminology coding system (SNOMED CT) provided a more complete coverage of desired terms than either of the two focused coding systems (ICF and ICNP). However there are important caveats to this statement. First, the ICF and ICNP are both classification systems, not formal terminologies. The coded terms within both systems reflect a high-level grouping of data, not an exhaustive list of all possible terms that could be classified into specific groups. Of note, both the ICF and ICNP were developed with intent to expand their content over time. Second, both the ICF and the ICNP classification systems provide textual definitions of each coded term. If the definitions within the ICF and ICNP were formally expressed and coded, a more extensive content coverage would have been evident. SNOMED CT does not provide textual definitions of terms. The meaning of terms must be inferred based on the placement of the term within the SNOMED CT hierarchies. This presents an obvious source of potential error in any content coverage study.

As yet, there is no recommendation from the NCVHS on the use of single, comprehensive health care terminology such as SNOMED CT or on an alternative federated approach with many different systems providing terms. Should the NCVHS recommend a single comprehensive reference terminology (for example, SNOMED CT), classification systems such as the ICF and ICNP could be rolled into such a terminology system in ways that retain the intent and focus of those classification systems. This will require significant development work for both the ICF and the ICNP in order to formally express their structure in a manner that is compatible with the reference terminology system. Alternatively, should the NCVHS recommend a federated approach whereby multiple large and small scale systems are used, similar development work will be required in order to integrate and assure interoperability of various coding systems within and across electronic health information systems.

Implications Related to Patient Medical Record Information System Developments

A standards-based information infrastructure is needed for long-term care PMRI systems, just as such an infrastructure is needed in other areas of health care. In particular, the presence of a uniform data system for expressing terminological data would enable quality reporting as a "by-product" of care. More importantly, such a terminology system is critical in order to build automated alerts and decision support systems that would enable enhancements to the care provided. The convergence of "best practices" with information systems requires a highly coordinated approach between terminology systems, documentation systems, and the standards of care suggested in the literature such as the ACOVE indicators that point to best practices. Electronic point of service documentation using a terminology system that is recognized by the all of the software applications that interface with that documentation would enable, for example, prompts to be issued as reminders to care providers around practice guidelines such as those published by

ACOVE. Further, failure to use standardized terminologies in electronic health information systems will increase costs and slow the adoption of interoperable PMRI systems.

Moving forward towards the NHII model for long-term care requires that standards for encoding clinical data, sending messages, and document architecture be adopted.

Experts in the development of health information systems agree that achieving the vision of the NHII requires Federal and private partnerships around the development, maintenance and dissemination of clinical terminologies. Among the recommendations made by the NCVHS to the Secretary of HHS is federal involvement in the selection of standards for patient medical record information, early adoption of PMRI standards by the Federal government, conformance testing and licensure of clinically specific terminologies, and funding for demonstration projects and research on improved clinical data capture (http://ncvhs.hhs.gov/reptrecs). Long-term care is an area of health care where there would likely be immediate benefits from the development of electronic health information systems.

To facilitate the evolution of the NHII first requires commitment to and adoption of standards by system developers, vendors, and purchasers; reaching consensus on the role of the federal government as a facilitator; continuing standards development, and providing financial resources. Until recently, standards development was seen largely as an industry responsibility because no federal funding has been allocated for this purpose. After standards are fully developed, subsequent efforts will be required that emphasize collaborations and implementations.

Sufficient progress has been achieved in our understanding of functioning characteristics, achievable reporting goals, information systems standards, and formal logics to permit the formation and defense of the vision proposed. However, many gaps exist in our underlying patient

record model, standards specifications, and terminology logics. Each of these gaps defines a body of cross-cutting research to close them. Harmonization of this research, to ensure the comparability and interoperability of the patient data elements, would afford obvious efficiencies.

Implications for the MDS

A reference terminology such as SNOMED CT is an essential underpinning of the NHII. An evolution from stand-alone reports such as the MDS to reports that are derived from clinical documentation systems requires close attention to terminology and other NHII related standards that will enable the re-use of clinical data across *multiple* applications (e.g., clinical decision support, alerts, quality monitoring, and reimbursement). The development and implementation of electronic patient medical record information systems that adhere to data standards required to achieve the NHII vision is a critical strategy for improving the quality of care in nursing homes.

This means that the development of an electronic clinical record for nursing homes and the derivation of quality monitoring and reporting from those clinical records must evolve in a fashion that is highly coordinated with the standards that will enable the NHII vision. The standards around clinical terminology systems that will allow the NHII vision to become a reality are particularly important to embrace. Failure to do so will only continue and exacerbate provider data collection burden and limit the scope, and, therefore, utility of the NHII for improving the quality of care in nursing homes.

Summary

The IOM report on computer based patient records concluded "computerized clinical data [are] a prerequisite for the safe provision of quality care" (38). Similarly, in its report on the quality of long-term care the IOM suggests that the development of computer based record systems is an

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essential strategy in improving the quality of care (18). Underlying this is the basic understanding that key documentation systems are not separate and removed from persons providing care. This report has illustrated that: (1) current nursing home reporting requirements do not completely reflect the information needed at the point of care to deliver quality of care or to subsequently monitor nursing home quality; and (2) work is needed to extend clinical terminologies so that they reflect the essential data elements required for delivering quality care.

Point of care clinical data captured in an integrated electronic health information system needs to be seen as a business imperative, both as a means of reducing documentation burden and improving accuracy, and, most importantly, as a means of supporting improvements in the quality of care. Although patient medical record information systems are not yet widely implemented in long-term care facilities, the IOM and others have identified the need for such initiatives as a way to substantially contribute to quality of care enhancements across the healthcare continuum. Development of electronic information systems will be slowed without public policy that supports and encourages the adoption of standards for messages, clinical document architecture, and terminologies.

The technology required to support the NHII vision of a distributed health information system is available, representing dramatic developments in the technical infrastructure of health care systems since the MDS was first developed. We can now support through technology assistance a patient and practice-centered approach that was the goal of the MDS efforts in the first place.

However achieving the vision awaits a concerted and coordinated national effort, including public and private efforts to support the adoption of standardized terminology systems, and research and demonstration efforts needed to extend inter-operable electronic clinical information systems into long-term care. In addition, work will be needed to build federal and state payment and quality monitoring policies using a well-developed terminology system that is a part of the NHII.

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Appendix A: ACOVE Indicators

Pressure Ulcers

Pain Management

Urinary Incontinence

ACOVE Indicators: Pressure Ulcers

Risk assessment	IF a vulnerable elder is admitted to an intensive care unit or a medical or surgical unit of a hospital and cannot reposition himself or herself or has limited ability to do so, THEN risk assessment to pressure ulcers should be done on admission.
Preventive intervention	IF a vulnerable elder is identified as at risk for pressure ulcer development or a pressure ulcer risk assessment score indicates that the person is at risk. THEN a preventive intervention addressing repositioning needs and pressure reduction (or management of tissue loads) must be instituted within 12 hours
Nutritional intervention	IF a vulnerable elder is identified as at risk for pressure ulcer development and has malnutrition (involuntary weight loss of > 10% over 1 year or low albumin or prealbumin levels,) THEN nutritional intervention or dietary consultation should be instituted.
Evaluation	IF vulnerable elder presents with a pressure ulcer, THEN the pressure ulcer should be assessed for location, depth, and stage, size, and presence of necrotic tissue.
Management	IF a vulnerable elder presents with a clean full-thickness pressure ulcer and has no improvement after 4 weeks of treatment, THEN the appropriateness of the treatment plan and the presence of cellulitis or osteomyelitis should be assessed. IF a vulnerable elder presents with a partial –thickness pressure ulcer and has no improvement after 2 weeks of treatment, THEN the appropriateness of the treatment plan should be assessed.
Debridement	IF a vulnerable elder presents with a full-thickness sacral or trochanteric pressure ulcer covered with necrotic debris or eschar, THEN debridement by using sharp, mechanical, enzymatic, or autolytic procedures should be done within 3 days of diagnosis
Cleaning	IF a vulnerable elder has a stage 2 or greater pressure ulcer, THEN topical antiseptic should not be used on the wound.
Systemic infection	IF a vulnerable elder with a full-thickness pressure ulcer presents with systemic signs and symptoms of infection, such as elevated temperature, leukocytosis, confusion, and agitation, and these signs and symptoms do not have another identified cause, THEN the ulcer should be debrided of necrotic tissue within 12 hours IF a vulnerable elder with a full-thickness pressure ulcer presents with systemic signs and symptoms of infection, such as elevated temperature, leukocytosis confusion, and agitation, and these signs and symptoms do not have another identified cause, THEN a tissue biopsy or needle aspiration sample should be obtained and sent for culture and sensitivity testing within 12 hours.
Topical Dressing	IF vulnerable elder presents with a clean full-thickness or a partial-thickness pressure ulcer, THEN a moist-healing environment should be provided with a topical dressing.

ACOVE Indicators: Pain Management

Screening for pain	ALL vulnerable elders should be screened for chronic pain during initial evaluation period. ALL vulnerable adults should be screened for chronic pain every 2 years.
Target history and physical examination	IF a vulnerable adult has a newly reported chronic pain condition, THEN a targeted history and physical examination should be initiated within 1 month.
Addressing risks of NSAIDs	IF a vulnerable adult ahs been prescribed a cyclooxygenase nonselective NSAID for the treatment of chronic pain, THEN the medical record should indicate whether he or she has a history of peptic ulcer disease and, if a history is present, justification of the NSAID should be documented
Constipation with opioid use	IF a vulnerable elder with chronic pain is treated with opioids, THEN he or she should be offered a bowel regimen, or the medical record should document the potential for constipation or explain why bowel treatment is not needed.
Treating pain	IF a vulnerable elder has a newly reported chronic painful condition, THEN treatment should be offered.
Reassessment of pain control	IF a vulnerable elder is treated for a chronic painful condition, THEN he or she should be assessed for a response within 6 months.
Related indicators	Evaluate depression in patients with chronic pain. Palliative care. Educate concerning side effects of new medication. Avoid meperidine. Assess pain and function annually for osteoarthritis. Acetaminophen use for osteoarthritis. NSAID use for osteoarthritis.

ACOVE Indicators: Urinary Incontinence

Initial evaluation	ALL vulnerable elders should have documentation of the presence or absence of urinary incontinence during the initial evaluation.
Annual evaluation	ALL vulnerable elders should have annual documentation of the presence or absence of urinary incontinence.
Targeted history	IF a vulnerable elder has a new urinary incontinence that persists for more than 1 month or urinary incontinence at the time of a new evaluation, THEN a targeted history should be obtained that documents each of the following: 1) characteristics of voiding, 2) ability to get to the toilet, 3) previous treatment for urinary incontinence, 4) importance of the problem to the patient, and 5) mental status.
Targeted physical examination	IF a vulnerable elder has new urinary incontinence that persists for more than 1 month or urinary incontinence at the time of a new evaluation, THEN a targeted physical examination should be performed that documents 1) rectal examination 2) a genital system examination (including a pelvic examination for women).
Diagnostic tests	IF a vulnerable elder has a new urinary incontinence that persists for more than 1 month or urinary incontinence at the time of a new evaluation, THEN a dipstick urinalysis and post-void residual should be obtained.
Discussion of treatment options	IF a vulnerable elder has a new urinary incontinence or urinary incontinence at the time of a new evaluation, THEN treatment options should be discussed.
Behavioral therapy	IF a cognitively intact vulnerable elder who is capable independent toileting has documented stress, urge, or mixed incontinence without evidence of hematuria or high post-void residual, THEN behavioral treatment should be offered.
Urodynamic testing	IF a vulnerable elder undergoes surgery or periurethral injections for urinary incontinence, THEN subtracted cystometry should be performed before the procedure.
Surgery for stress incontinence	IF a female vulnerable elder has documented stress urinary incontinence caused by isolated intrinsic sphincter deficiency or intrinsic sphincter deficiency with coexistent hypermobility, and she undergoes surgical correction, THEN a sling or artificial procedure should be used.
Catheter use	IF a vulnerable elder has clinically significant newly discovered overflow urinary incontinence and indwelling urethral catheterization is used, THEN there should be documentation that the patient is not a candidate for alternative interventions as a result of severe physical or mental impairments or does not want to alternative interventions

Appendix B: Terms Abstracted from Domain Experts Reports

Domain Focus	Purpose for Which Term Provides Information	Terms
Pressure Ulcer Risk		
	Provider information	NA ,RN, LPN
	Patient tracking information	
	Patient information	Age, gender
	Pressure ulcer	Assess for recurrence of pressure ulcer
		Location of pressure ulcer
		Stage of pressure ulcer
		Ulcer healing
	Risk status	At risk for developing pressure ulcers
		High risk for pressure ulcers
		Risk assessment tools
		Braden scale
		Norton scale
		Skin inspection
		Periodic reassessment
	Cognition/Mental status	Comatose
		Cognitive skill
		Distracted
		Awareness
		Restlessness
		Lethargy
		Mental function
		Altered level of consciousness
		Depression score
		Mental status
	Can request help	Speech
		Verbal responses
	Ability to move	Bed mobility
	Activity	Bed bound
	Mobility	Chair bound
		Transfer ability
		Walking ability
		Locomotion
		Dressing ability
		Motion of: neck, arm, hand, leg, foot;
		ADL function
		Activities of daily living
		Restraint use
		Body control
		Mobility device
		Difficulty with repositioning

	Impaired ability to reposition
	Immobility
	Spinal cord injury
	Physical status
Nutrition	Eating ability
	Nutritional intake
	Oral/nutritional status
	Oral problems
	Oral nutritional supplements
	Enteral feeding
	Modular products
	Vitamin/mineral supplements
	Weight loss
	BMI
	Poor meal intake
	Dietary intake
	Albumin
	Nitrogen balance
	Nutritional status
	Dietary intake of protein
	Dietary intake of calories
	Malnutrition
	Nutrition screening
	Nutritional assessment
Risk for moisture exposure	Toilet use
Moisture	Personal hygiene
	Bathing
	Bowel incontinence
	Bladder incontinence
	Briefs
	Protective padding
	Underpads
	Skin hydration
Pressure	Bony prominence
Risk for delayed healing	Infections
Outcome and risk factor	History of ulcers
	Hospital stays
Risk for decreased tissue perfusion	Skin pliability
	Tobacco use
	CABG
Treatment for pressure ulcers	Ulcer care plan
	Application of dressings
	Clean dry dressings
	Dressings that keep ulcer bed continuously moist

Protective dressings
Cleanse wound
Mild cleansing agent
Whirlpool treatment
Wet to dry dressings
Debridement
Topical debriding agents
Autolytic debridement
Enzymatic debridement
Mechanical debridement
Wound irrigation
Foam
Gel
Growth factors
Hormones
Hyperbaric oxygen
Infrared ultraviolet
Hydrotherapy
Normal saline
Topical agents
Topical aminoglycoside treatment
Topical antibiotics
Topical treatment with iodine containing agents
Avoid massage over bony prominences
Moisturizers
Lubricants (corn starch and cream)
Electrical stimulation therapy
Low energy laser irradiation
Assisted oral feeding
Oral supplements
Devices that totally relieve pressure
Distribution of weight
Proper postural alignment
Characteristics of support surfaces
Dynamic support surface
Low air loss bed
Pressure relief
Pressure reducing beds
Pressure reducing mattresses
Pressure reducing overlays
Maintain position in bed or chair
Nutritional management
Aggressive nutritional interventions
Air fluidized beds

		Plan of nutritional support
		Patient education
		Repositioning schedule
		Surgical flap
		Postoperative viability of the surgical site
		Evaluate adequacy of treatment
	Condition factors	Radiation treatment
	Fiction/shear	Friction injuries
		Bed linen to move
		Lifting devices
		Minimize force and friction
		Positioning devices
		Transferring support
		Turning techniques
Chronic Pain		
	Risk factors for chronic pain in long term care facilities	Presence of diagnoses known to be painful: osteoarthritis, low back pain, fibromyalgia, spinal stenosis, post-herpetic neuralgia, peripheral neuropathy, myofascial pain syndromes, vasogenic claudication, phantom limb pain, headaches, vasculitic pain syndromes, osteoporosis with fractures, cancer, contractures, peripheral vascular disease, rheumatoid arthritis
	Risk of unrecognized and thus untreated pain	Dementia
		Delirium
	Location	Pain map
		Drawing
		Description
	Intensity or severity of pain	Numeric estimate (0-100)
		Verbal descriptors scale: no pain, moderate, severe, excruciating, worst pain possible, most intense pain imaginable
		Faces pain Scale
	Quality	Terms within McGill pain questionnaire
	Duration	Intermittent, continuous, lasting minutes or hours
	Pattern	When starts, what started it, what makes it better, what makes it worse
	Pain behaviors	Facial (wrinkled forehead, tightly closed eyes, grimacing, frowning)
		Nonverbal behavior (bracing, rubbing, guarding)
		Vocalizations (crying, yelling, groaning, moaning)

	Nonverbal indicators of discomfort	Aggressive, crying, fearful, negative vocalization, noisy respirations, pacing, repetitive, restlessness, rocking, confusion irritability, increased activity, withdrawal, tense, calling out, grunting, knees pulled up Other changes in usual activities or behavior patterns/routines
	Impact of pain on quality of life outcomes	Physical function, sleep, appetite, interpersonal relationships/interactions with others, mood (anxiety, depression), mental status (ability to think clearly/concentration/confusion), energy/fatigue
	Treatments	Pain intensity monitoring
		Appropriate use of medications
		Appropriate use of non-pharmacologic interventions
Urinary incontinence		
	Targeted history Mental status Characteristics of voiding and non-invasive bladder diagnosis Ability to toilet Prior treatment for incontinence Importance of problem to resident	MDS recall scale, MDS item B3, or Cognitive performance scale derived from MDS items Frequency of incontinence Status of incontinence: day and night Symptoms on urination Symptoms to distinguish between urge incontinence (short interval between sensation to void and bladder contraction) and stress incontinence (urine loss during physical movements)
		Mobility problems on MDS and provider notes
	Targeted Physical	Rectal exam to exclude fecal impaction Skin exam to evaluate skin problems associated with urinary incontinence Genital system exam to identify physical abnormalities that may explain incontinence (e.g., pelvic prolapse)
	Factors Associated with UI	Lab reports primary care provider notes
	Toileting responsiveness as-	How often person voids when prompted on

sessments	a routine basis
	Voiding record
	Non-invasive diagnoses of bladder function
Urodynamic analyses of bladder functioning	
Interventions	Prompted toileting
	Prompted voiding
	Scheduled toileting
	Timed voiding

Appendix C: Examples of MDS-Derived Quality Indicators

Pressure Ulcers

Bladder or Bowel Incontinence

Prevalence of Stage 1-4 Pressure Ulcer

Numerator:
Residents with pressure ulcers (Stage 1-4) on most recent assessment.

Denominator:
All residents on most recent assessment.

MDS 2.0 quarterly variable definition:
Pressure ulcer (M2a > 0, or 13 = ICD-9 CM 707.0)

Risk adjustment:
High risk: Impaired transfer or bed mobility (G1a or b = 3 or 4-Box A)
        OR comatose (B1 = 1),
OR malnutrition (13 = ICD-9 CM 260, 261, 262, 263.0, 263.1, 263.2, 263.8, or 263.9)
OR end stage disease (J5c is checked) most recent assessment
Low risk: all others at most recent assessment.

Prevalence of Bowel or Bladder Incontinence

Numerator:
Residents who were frequently incontinent or incontinent on most recent assessment

MDS 2.0 quarterly variable definition:
Bladder incontinence (H1b=3 or 4)
Bowel incontinence (H1a=3 or 4)

Denominator: All residents, except as noted in exclusion
Exclude: Residents who are comatose residents (B1=1); OR have indwelling catheter (H3d is checked); OR have an ostomy (H3i is checked) at most recent assessment

High risk = Severe cognitive impairment AND short-term memory problems (B4=3 and B2a=1) OR Totally ADL dependent in mobility ADLs (G1 a, b, e-Box A self-performance = 4 in all areas) at most recent assessment

Low risk: all others at most recent assessment

Appendix D: Examples of MDS-Derived Quality Measures

Pressure Ulcers

Pain

Percent of Residents with Pressure Sores with Additional Level of Risk Adjustments (A QM for long-stay residents)

Numerator: number of residents with pressure ulcers (stage 1-4) on full or quarterly assessment (M2A>0 or I3a-e=707.0)

Denominator: all residents with valid full (AA8a=01, 02, 03, 04) or quarterly assessment (AA8a=05 10)
Exclusions: most recent assessment is the admission assessment (AA8a=01); the QM is not triggered (resident is not included numerator) AND the value of M2a is missing on the target assessment.

Resident is a facility with a chronic care sample size =0 (i.e., over the last 12 months no residents with a non-PPS assessment - AA8a= 01 and AA8b=blank or 6)

Facility Admission Profile
Considers prevalence of stage 1-4 PU (M2a>0 OR I3a-e=707.0 among admissions (AA8a=01) occurring over the previous 12 months

Numerator: admission assessments (AA8a=01) w/ M2A.0 **OR** *I3a-e=707.0*
Denominator: all admission assessments (AA8a=01)
Exclusions: admission assessments (AA8a=01) that do not satisfy the numerator conditions **AND** *have missing data on M2a.*

Percent of Short-Stay Residents with Pain (A QM for short-stay residents)

Uses SNF PPS 14 day assessment (AA8b=7) with valid preceding 5 day SNF PPS assessment (AA8b=1)

Numerator: number of residents who experience moderate pain at least daily (J2a=2 and J2b=2) **OR** horrible excruciating pain at any frequency (J2b=3) as noted on the SNF PPS 14 day

Denominator: all residents with valid SNF PPS 14 day assessment (AA8b= 7)

Exclusions: J2a or J2b missing from SNF PPS 14 day assessment; J2a or J2b inconsistent on the SNF PPS 14 day assessment (e.g., coding pain frequency as "no pain" while simultaneously coding intensity of pain as "moderate"); resident is in a facility with a post-acute care sample size =0 (i.e., SNF PPS 5 day assessment AA8b=1 over the last 12 months).

Appendix E: Contact Information, Terminology Coding Systems

SNOMED CT

Purpose as reported by developers: Terminology system that facilitates coding and retrieval of

clinically relevant information

Copyright: SNOMED International, a division of the College of American Pathologists (CAP)

Contact information: SNOMED International
                  325 Waukegan Road
                  Northfield, IL 60093-2750
                  Phone: (800) 323-4040 ext. 7700 U.S. and Canada
                  Phone: (847) 832-7700
                  E-mail: snomed@cap.org

ICF

Purpose reported by developers: A classification of health and health related domains that de-

scribe body functions and structures, activities and participation.

Copyright: World Health Organization (WHO)

Contact information: World Health Organization
                  Coordinator Classification, Assessment Surveys and Terminology
                  Unit 20, Avenue Appia 1211
                  Geneva, Switzerland
                  E-mail: ustunb@who.int

ICNP

Purpose reported by developers: Facilitate the crossmapping of local terms and existing nursing

vocabularies and classifications

Copyright: International Council of Nurses

Contact information: ICNP® Programme Director
                  Marquette University, College of Nursing
                  P.O. Box 1881
                  Milwaukee, WI 53201 USA
                  FAX: (414) 288 1939
                  E-mail: amy.coenen@marquette.edu

Appendix F: Terms Abstracted from the MDS

MDS Terms Classified as "Administrative Information" (n=87)

MDS
Identification Information
Resident Name
First
Middle
Last
Jr/Sr
Gender
Birthdate
Race/ethnicity
Social security number and Medicare Number
Facility Provider Number
State number
Federal Number
Medicaid Number
Reasons for Assessment
Primary reason for assessment
Admission assessment
Annual assessment
Significant change in status assessment
Significant correction of prior full assessment
Quarterly review assessment
Significant correction of prior quarterly assessment
Medicare 5 day assessment
Medicare 30 day assessment
Medicare 60 day assessment
Medicare 90 day assessment
Medicare readmission/return assessment
Other state required assessment
Medicare 14 day assessment
Other Medicare required assessment
Signature of Persons Completing a Portion of the Assessment
Signature
Title
Date
Demographic Information
Date of Entry
Admitted from
Zip Code of Prior Primary Residence
Date Background Information Completed
Not applicable no MR/DD
Identification and Background Information
Middle initial
Room Number

Assessment Reference Date
Last day of MDS observation period
Marital Status
Medical Record Number
Current Payment Sources for NH Stay
Medicaid per diem
Medicare per diem
Medicare ancillary part A
Medicare ancillary part B
CHAMPUS per diem
VA per diem
Self or family pays for full per diem
Medicaid resident liability of Medicare co-payment
Private insurance per diem
Other per diem
Significant change in status assessment
Discharged return not anticipated
Discharged return anticipated
Discharged prior to completing initial assessment
Reentry
Codes for assessments required for Medicare PPS or the state
Responsibility/Legal Guardian
Legal guardian
Other legal oversight
Durable power of attorney/health care
Durable power attorney/financial
Family member responsible
Advanced Directives
Living will
Do not resuscitate
Do not hospitalize
Organ donation
Autopsy request
Hospital Stay(s)
Emergency Room (ER) Visit(s)
Physician Orders
Assessment Information
Participation in Assessment
Resident
Family
Significant other
Signature of Person Coordinating the Assessment
Patient responsible for self

MDS Terms Classified as "Resident History" (n=143)

Private home without home health services
Private home with home health services
Board and care assisted living group home
Nursing home
Acute care hospital
Psychiatric hospital MR/DD facility
Rehabilitation hospital
Lived Alone (Prior to entry)
Residential History 5 Years Prior to Entry
Prior stay at this nursing home
Stay in other nursing home
Other residential facility - board and care home, assisted li
MH/psychiatric setting
MR/DD setting
Lifetime Occupation(s)
Education
No schooling
8th grade/less
9-11 grades
High school
Technical or trade school
Some college
Bachelor's degree
Graduate degree
Language
English
Spanish
French
Primary language
Down's syndrome
Autism
Epilepsy
Other organic condition related to MR/DD
MR/DD with no organic condition
Mental health history
Conditions related to MR/DD status
MR/DD with organic condition
Other organic condition related to MR/DD
MR/DD with no organic condition
Customary Routine
Cycle of Daily Events
Stays up late at night
Naps regularly during day
Goes out 1+ days a week

Stays busy with hobbies, reading or fixed daily routine
Spends most of time alone of watching TV
Moves independently indoors
Use of tobacco products at least daily
Eating Patterns
Distinct food preferences
Eats between meals all or most days
Use of alcoholic beverage(s) at least weekly
ADL Patterns
No change in ADL function
Improved
Deteriorated
In bedclothes much of day
Wakens to toilet all or most nights
Has irregular bowel movement patterns
Showers for bathing
Bathing in PM
Involvement Patterns
Daily contact with relatives/close friends
Usually attends church, temple, synagogue
Finds strength in faith
Daily animal companion/presence
Involved in group activities
Past Roles
Frequently incontinent
Incontinent
Disease Diagnosis
Diseases
Endocrine/metabolic/nutritional
Diabetes mellitus
Hyperthyroidism
Hypothyroidism
Heart/circulation
ASHD
Cardiac dysrythmias
Congestive heart failure
Deep vein thrombosis
Hypertension
Hypotension
Peripheral vascular disease
Other cardiovascular disease
Musculoskeletal
Arthritis
Hip fracture
Missing limb
Osteoporosis

Pathological bone fracture
Neurological
Alzheimer's disease
Aphasia
Cerebral palsy
Cerebrovascular accident
Dementia other than Alzheimer's disease
Hemiplegia/hemiparesis
Multiple sclerosis
Paraplegia
Parkinson's disease
Quadriplegia
Seizure disorder
Transient ischemic attack
Traumatic brain injury
Psychiatric/mood
Anxiety disorder
Depression
Manic depression
Schizophrenia
Pulmonary
Asthma
Emphysema
Sensory
Cataracts
Diabetic retinopathy
Glaucoma
Macular degeneration
Allergies
Anemia
Cancer
Renal failure
Infections
Antibiotic resistant infection
Clostridium difficile
Conjunctivitis
HIV infection
Pneumonia
Respiratory infection
Septicemia
Sexually transmitted disease
Tuberculosis
Urinary tract infection in last 30 days
Viral hepatitis
Wound infection
Other Current or more Detailed Diagnoses and ICD-9 Codes

Accidents
Fell in past 30 days
Fell in past 31-180 days
Hip fracture in last 180 days
Other fracture in last 180 days
End-stage disease
History of Resolved Ulcers

MDS Terms Classified as "Assessments" (n=273)

Cognitive Patterns
Comatose
Memory
Short-term memory OK
Long-term memory OK
Memory/recall Ability
Current season
Location of own room
Staff names/faces
That he/she is in a nursing home
Cognitive skills for Daily Decision Making
Indicators of Delirium-Periodic Disordered Thinking/Awareness
Easily distracted
Periods of altered perception or awareness of surroundings
Episodes of disorganized speech
Periods of restlessness
Periods of lethargy
Mental function varies over the course of the day
Change in Cognitive Status
Communication/Hearing patterns
Hearing
Hears adequately
Minimal difficulty hearing
Hears in special situations only
Highly impaired hearing
Communication Devices/Techniques
Hearing aid present and used
Hearing aid present and not used regularly
Other receptive comm. Techniques used
Modes of Expression
Speech
Writing messages to express or clarify needs
American sign language or Braille
Signs/gestures/sounds
Communication board
Making Self Understood

Understood
Usually understood
Sometimes understood
Rarely/Never understood
Speech clarity
Clear speech
Unclear speech
No speech
Ability to Understand Others
Understands
Usually understands
Sometimes understands
Rarely/Never understands
Change in Communication/Hearing
Vision Patterns
Vision
Adequate
Impaired
Moderately impaired
Highly impaired
Severely impaired
Visual Limitations/Difficulties
Side vision problems
Experiences any of following:
Mood and Behavior Patterns
Indicators of Depression, Anxiety, Sad Mood
Verbal expressions of distress
Resident made negative statements
Repetitive questions
Repetitive verbalizations
Persistent anger with self or others
Self deprecation
Expressions of what appear to be unrealistic fears
Recurrent statements that something terrible is about to happen
Repetitive health complaints
Repetitive anxious complaints/concerns
Sleep cycle issues
Unpleasant mood in morning
Insomnia/change in usual sleep pattern
Sad, apathetic, anxious appearance
Sad, pained, worried facial expressions
Crying, tearfulness
Repetitive physical movements
Loss of interest
Withdrawal from activities of interest
Reduced social interaction

Mood Persistence
Change in Mood
Behavioral Symptoms
Wandering
Verbally abusive behavioral symptoms
Physically abusive behavioral symptoms
Socially inappropriate/disruptive behavioral symptoms
Resists care
Change in Behavioral Symptoms
Psychosocial Well-Being
Sense of Initiative/Involvement
At ease interacting with others
At ease doing planned or structured activities
At ease doing self-initiated activities
Establishes own goals
Pursues involvement in life of facility
Accepts invitations into most group activities
Unsettled Relationships
Covert/open conflict with or repeated criticism of staff
Unhappy with roommate
Unhappy with residents other than roommate
Openly expressed conflict/anger with family/friends
Recent loss of close family member/friend
Does not adjust easily to change in routines
Strong identification with past roles and life status
Expresses sadness/anger/empty feeling over lost roles/status
Resident perceives that daily routine is very different from prior pattern in the community
Physical Functioning and Structural Problems
ADL Self Performance/ADL support provided
Bed mobility
Transfer
Walk in room
Walk in corridor
Locomotion off unit
Dressing
Eating
Toilet use
Personal hygiene
Bathing
ADL self-performance
Independent
Supervision
Limited assistance
Extensive assistance
Total dependence
Activity did not occur

ADL support provided
No setup or physical help from staff
One person physical assist
Two + person physical assist
Test for Balance
Balance while standing
Balance while sitting
Functional Limitation in Range of Motion
Neck
Arm
Hand
Leg
Foot
Other limitation or loss
Modes of Locomotion
Cane/walker/crutch
Wheeled self
Other person wheeled
Wheelchair primary mode of locomotion
Modes of Transfer
Bedfast all or most of time
Bed rails used for bed mobility or transfer
Lifted manually
Lifted mechanically
Transfer aid
Task Segmentation
ADL Functional Rehabilitation Potential
Resident believes he/she is capable of increased independence
Direct care staff believe resident is capable of increased in
Resident able to perform tasks/activity but is very slow
Difference in ADL self-performance or ADL support, comparing mornings to evenings
Change in Function
Continence in Last 14 Days
Continence Self-Control Categories
Continent
Usually Continent
Occasionally incontinent
Bowel continence
Bladder continence
Bowel elimination pattern
Regular
Constipation
Diarrhea
Fecal impaction
Did not use toilet room/commode/urinal
Change in urinary continence

Health Conditions
Problem Conditions
Indicators of fluid status
Weight gain or loss of 3 or more pounds within a 7 day period
Inability to lie flat due to shortness of breath
Dehydrated; output exceeds input
Insufficient fluid; did not consume all/almost all liquids provided during last 3 days
Delusions
Dizziness/vertigo
Edema
Fever
Hallucinating
Internal bleeding
Recurrent lung aspirations in last 90 days
Shortness of breath
Syncopy
Unsteady gait
Vomiting
Pain Symptoms
Frequency
Intensity
Pain Site
Back
Bone
Chest pain while doing usual activities
Headache
Hip
Incisional pain
Joint pain
Soft tissue pain
Stomach pain
Stability of Conditions
Conditions/diseases make resident's cognitive, ADL, mood or b
Resident experiencing an acute episode or a flare-up of a rec
Oral/Nutritional Status
Oral Problems
Chewing problem
Swallowing problem
Mouth pain
Height
Weight
Weight Change
Weight loss
Weight gain
Nutritional Problems
Complains about the taste of many foods

Regular or repetitive complaints of hunger
Leaves 25% or more of food uneaten at most meals
Oral/Dental Status
Oral Status and Disease Prevention
Debris present in mouth prior to going to bed at night
Has dentures or removable bridge
Some/all natural teeth lost
Broken, loose, or carious teeth
Inflamed gums
Daily cleaning of teeth/dentures or daily mouth care
Skin condition
Ulcers
Stage 1
Stage 2
Stage 3
Stage 4
Type of Ulcer
Pressure ulcer
Stasis ulcer
Other skin Problems or Lesions Present
Abrasions
Burns
Open lesions other than ulcers, rashes, cuts
Rashes
Skin desensitized to pain or pressure
Skin tears or cuts
Surgical wounds
Resident has one or more foot problems
Infection of the foot
Open lesions on the foot
Activity Pursuit Patterns
Time Awake
Average Time Involved in Activities
Preferred Activity Settings
General Activity Preferences
Prefers Change in Daily Routine
Type of activities in which resident is currently involved
Extent of resident involvement in activities
Intake/output
Evaluation by a licensed mental health specialist in last 90 days
Transfer
Walking
Dressing or grooming
Eating or swallowing
Amputation/prosthesis care
Communication

Abnormal Lab Values
Discharge Potential and Overall Status
Discharge Potential
Resident expresses/indicates preference to return to the community
Resident has a support person who is positive towards discharge
Stay projected to be of a short duration
Overall Change in Care Needs

MDS Terms Classified as "Treatments" (n= 93)

Feeding restrictions
Medication restrictions
Other treatment restrictions
Visual Appliances
Glasses
Contacts lenses
Magnifying glass
Appliances and programs
Any scheduled toileting plan
Bladder retraining program
External catheter
Indwelling catheter
Intermittent catheter
Pads/briefs used
Enemas/irrigation
Ostomy present
Nutritional Approaches
Parenteral/IV
Feeding tube
Mechanically altered diet
Syringe
Therapeutic diet
Dietary supplement between meals
Plate guard, stabilized built-up utensil
On a planned weight change program
Parenteral or Enteral Intake
Code the proportion of total calories the resident received through parenteral or tube feedings in the last 7 days
Skin Treatments
Pressure relieving device for chair
Pressure relieving device for bed
Turning/repositioning program
Nutrition or hydration intervention to manage skin problems
Ulcer care
Surgical wound care
Application of dressings

Application of ointments/ medications
Other preventative or protective skin care
Foot Problems and Care
Received preventive or protective foot care
Medications
Number of Medications
New Medications
Injections
Days Received the Following Medications
Antipsychotic
Antianxiety
Antidepressant
Hypnotic
Diuretic
Special Treatments and Procedures
Special Treatments, Procedures, and Programs
Special care
Treatments
Chemotherapy
Dialysis
IV medication
Monitoring acute medical condition
Ostomy care
Oxygen therapy
Radiation
Suctioning
Tracheostomy care
Transfusions
Ventilator or respirator
Programs
Alcohol/drug treatment program
Alzheimer's/dementia special care unit
Hospice care
Pediatric care
Respite care
Training in skills required to return to the community
Therapies
Occupational therapy
Physical therapy
Respiratory therapy
Psychological therapy
Intervention Programs for Mood, Behavior, Cognitive Loss
Special behavior symptoms evaluation program
Group therapy
Resident-specific deliberate changes in the environment to address mood/behavior patterns
Reorientation

Nursing Rehabilitation/Restorative Care
Range of motion (active)
Range of motion (passive)
Splint of brace assistance
Training and skill practice in:
Devices and Restraints
Bed rails
Full bed rails on all open sides of bed
Other types of side rails used
Trunk restraint
Limb restraint
Chair prevents rising

MDS Terms Classified as "Other" (n=43)

Section
If other, specify
Not applicable
Unknown
Face Sheet Signatures
Signatures of persons completing face sheet
Signature of RN assessment coordinator
Title
Original or corrected copy of form
Date of Reentry
other
none of above
None
1% to 25%
26% to 50%
51% to 75%
76% to 100%
Code the average fluid intake per day by IV or tube in last 7 days
1 to 500 cc/day
501 to 1000 cc/day
1001 to 1500 cc/day
1501 to 2000 cc/day
2001 or more cc/day
Morning
Afternoon
Evening
Own room
Day/activity room
Inside NH/off unit
Outside facility
Cards/other games

Crafts/arts
Exercise/sports
Music
Reading/writing
Spiritual/religious activities
Trips/shopping
Walking/wheeling outdoors
Watching TV
Gardening or plants
Talking or conversing
Helping others
Physician visits

Appendix G: Terms Provided by Domain Experts, Partial or No Matches

Domain Expert Terms for Which MDS Provided Partial or No Content Coverage

Domain Expert Terms for Which SNOMED CT Provided Partial or No Content Coverage

Terms From Domain Experts, Partial Match or No Match to MDS

Terms from Domain Expert	Partial Match MDS	No Match MDS
Pressure Ulcer Terms		
Adequacy of treatment		Adequacy of treatment
Air-fluidized bed	Pressure relieving device for bed	
Avoid positioning directly on the trochanter		Avoid positioning directly on the trochanter
Body control		Body control
Bony prominences		Bony prominence
Braden scale		Braden scale
Cellulitis		Cellulitis
Characteristics of support surfaces		Characteristics of support surfaces
Clean dressings	Application of dressings	
Complete history		Complete history
Complete physical examination		Complete physical examination
Debridement (sharp, mechanical, enzymatic, or autolytic)	Ulcer care	
Dietary intake of protein		Dietary intake of protein
Depression score		Depression score
Dietary intake of calories	Calories received through parenteral or tube feedings in last 7 days	
Dynamic support surface	Pressure relieving device for bed	
Educational program for prevention of pressure ulcers	Nursing rehabilitation/restoration "other"	
Electrical stimulation therapy	Ulcer care	
Eschar		Eschar
Exudate		Exudate
Film dressing	Ulcer care	
Friction		Friction
Friction injuries		Friction injuries
Hydrocolloid dressing	Ulcer care	
Hydrotherapy	Ulcer care	
Hyperbaric oxygen	Ulcer care	
Inspect skin at least once a day, if early treatment		Inspect skin at least once a day, if early treatment
Irrigation pressure		Irrigation pressure
Lifting devices		Lifting devices

Terms from Domain Expert	Partial Match MDS	No Match MDS
Low air-loss bed	Pressure relieving device for bed	
Lubricants to reduce friction injuries		Lubricants to reduce friction injuries
Modular products		Modular products
Moisture exposure on intact skin		Moisture exposure on intact skin
Mineral supplements		Mineral supplements
Normal saline for cleansing	Ulcer care	
Norton scale		Norton scale
Oral intake goals		Oral intake goals
Periodic reassessment (at least weekly)		Periodic reassessment
Poor meal intake		Poor meal intake
Positioning devices		Positioning devices
Positioning techniques		Positioning techniques
Postural alignment		Postural alignment
Protective films		Protective films
Protective dressings		Protective dressings
Protective padding		Protective padding
Range of motion		Range of motion
Risk for delayed healing		Risk for delayed healing
Risk for moisture exposure		Risk for moisture exposure
Risk for pressure ulcers		Risk for pressure ulcers
Shearing		Shearing
Sepsis		
Severity of illness		Severity of illness
Shift weight every 15 minutes	Nursing rehabilitation/restoration "other"	
Skin cleansed at routine intervals		Skin cleansed at routine intervals
Skin cleansed at time of soiling		Skin cleansed at time of soiling
Static support surface		Static support surface
Stryker frame		Stryker frame
Tissue viability of the surgical site (if operative repair of pressure ulcer)		Tissue viability of surgical site
Topical treatment with iodine containing agents	Application of ointments/medications	
Transferring support	Modes of transfer	
Treatment goals		Treatment goals
Ulcer care plan evaluated		Ulcer care plan evaluated
Vitamin supplements	Number of medications	
Whirlpool treatment	Ulcer care	

Terms from Domain Expert	Partial Match MDS	No Match MDS
Chronic Pain Terms		
Contractures		Contractures
Drawing of pain location		Drawing of pain location
Energy/fatigue		Energy/fatigue
Faces pain scale		Faces pain scale
Facial expressions (wrinkled forehead, tightly closed eyes, grimacing, frowning)	Sad, pained, worried facial expression	
Fibromyalgia		Fibromyalgia
Grunting	Making self understood	
Headaches		Headaches
Impact of pain on (quality of life outcomes, physical function, sleep, appetite, interpersonal relationships/interactions with others, mood, mental status)		Impact of pain on (quality of life outcomes)
Irritability	Verbal expressions of distress (e.g., repetitive anxious complaints/concerns)	
Knees pulled up		Knees pulled up
Lasting minutes or hours		Lasting minutes or hours
Low back pain		Low back pain
McGill pain questionnaire		McGill pain questionnaire
Monitoring pain intensity	Pain intensity	
Myofascial pain syndromes		Myofascial pain syndromes A
Non-pharmacologic interventions		Non-pharmacologic interventions
Nonverbal behaviors (bracing, rubbing, guarding)		Nonverbal behaviors (bracing, rubbing, guarding)
Numbness		Numbness
Osteoarthritis	Arthritis	
Pain behaviors		Pain behaviors
Pain intensity	Pain intensity	
Pain map		Pain map
Patient satisfaction associated with pain management		Patient satisfaction associated with pain management
Pattern of pain		Pattern of pain
Peripheral neuropathy		Peripheral neuropathy
Phantom limb pain		Phantom limb pain
Post-herpetic neuralgia		Post-herpetic neuralgia
Radiating pain		Radiating pain
Rheumatoid arthritis	Arthritis	

Terms from Domain Expert	Partial Match MDS	No Match MDS
Risk of unrecognized and thus untreated pain		Risk of unrecognized and thus untreated pain
Screening procedures		Screening procedures
Spinal stenosis		Spinal stenosis
Stabbing pain	Pain symptom	
Throbbing pain	Pain symptom	
Tingling		Tingling
Vasculitic pain syndromes		Vasculitic pain syndromes
Vasogenic claudication		Vasogenic claudication
Verbal descriptors scale		Verbal descriptors scale
What starts pain		What starts pain
What makes pain better		What makes pain better
What makes pain worse		What makes pain worse
When pain starts		When pain starts

Urinary Incontinence Terms

Terms from Domain Expert	Partial Match MDS	No Match MDS
Ability to toilet	Toilet use	
Characteristics of voiding and non-invasive bladder diagnosis		Characteristics of voiding and non-invasive bladder diagnosis
Factors Associated with UI		Factors Associated with UI
Genital system exam to identify physical abnormalities that may explain incontinence (e.g., pelvic prolapse)		Genital system exam to identify physical abnormalities that may explain incontinence (e.g., pelvic prolapse)
How often person voids when prompted on a routine basis		How often person voids when prompted on a routine basis
Importance of problem to resident		Importance of problem to resident
Lab reports		Lab reports
Non-invasive diagnoses of bladder function		Non-invasive diagnoses of bladder function
Primary care provider notes		Primary care provider notes
Prior treatment for incontinence		Prior treatment for incontinence
Prompted toileting	Any scheduled toileting plan	
Prompted voiding		
Rectal exam to exclude fecal impaction		Rectal exam to exclude fecal impaction
Skin exam to evaluate skin problems associated with urinary incontinence		Skin exam to evaluate skin problems associated with urinary incontinence
Status of incontinence: day and night	Bladder continence	

Terms from Domain Expert	Partial Match MDS	No Match MDS
Symptoms on urination		Symptoms on urination
Symptoms to distinguish between urge incontinence (short interval between sensation to void and bladder contraction) and stress incontinence (urine loss during physical movements)		Symptoms to distinguish between urge incontinence (short interval between sensation to void and bladder contraction) and stress incontinence (urine loss during physical movements)
Targeted history		Targeted history
Targeted physical		Targeted physical
Toileting responsiveness assessments		Toileting responsiveness assessments
Urodynamic analyses of bladder functioning		Urodynamic analyses of bladder functioning
Voiding record	Any scheduled toileting plan	Voiding record

Terms From Domain Experts, Partial Match or No Match to SNOMED-CT

Terms from Domain Expert	Partial Match, SNOMED CT	No Matching Term, SNOMED CT
Pressure Ulcer Terms		
Activity	Type of activity	Activity
Adequacy of treatment		Adequacy of treatment
Awareness	Consciousness	(SNOMED term "state of awareness" is a retired concept)
Bed bound	Bed ridden	
Bony prominences		Bony prominences
Braden scale		Braden scale
Can request help	Request for Ability to ask questions (Specific types of help)	Help
Chair bound	Confined to chair	
Characteristics of support surfaces		Characteristics of support surfaces
Condition factors		Condition factors
Difficulty with repositioning	Repositioning	Difficulty with repositioning
Distracted	Easily distracted	Distracted without modifier
Friction injuries		Friction injuries
Locomotion		Locomotion
Modular products		Modular products
Moisture		Moisture exposure
Motion of: neck, arm, hand, leg, foot	Motion Ability to move arm Ability to move hand Ability to move leg Ability to move foot	Motion
Norton scale		Norton scale
Periodic reassessment		Periodic reassessment
Poor meal intake	Food intake	Meal
Skin pliability	Skin assessment	Pliability
Ulcer care plan evaluated	Care plan Evaluation	Ulcer care plan
Verbal responses	Uses verbal communication	
Viability of the surgical site		(SNOMED term "surgical site" has been retired)

Chronic Pain Terms

Description	Symptom description NOS	Description
Drawing		Drawing
Faces pain scale	Finding of present pain intensity	Faces pain scale
Facial expressions (wrinkled forehead, tightly closed eyes, grimacing, frowning)	Grimaces	Wrinkled forehead Tightly closed eyes Frowning
Grunting	Vocalization	(note: snomed includes term grunting but "is_a" animal vocalization
Impact of pain on quality of life outcomes	Pain Determination of outcome	Impact Quality of life
Lasting minutes or hours	Time frame Intervals of minutes Intervals of hours	Lasting
Negative vocalization	Negative Vocalization	Negative vocalization
Nonverbal behavior (bracing, rubbing, guarding)		Nonverbal behavior (bracing, rubbing, guarding)
Nonverbal indicators of discomfort	Discomfort	Nonverbal indicators
Pain map		Map
Physical function		Physical function
Risk of unrecognized and thus untreated pain	Risk of Pain	Unrecognized Untreated
Vasculitic pain syndromes	Pain	Vasculitic pain syndromes
Withdrawal from activities of interest	Loss of interest	Withdrawal from activities

Urinary Incontinence Terms

Importance of problem to resident	Problem	Importance Resident
Targeted history	History taking Has focus	Targeted
Targeted physical	Physical exam Limited	Targeted

Appendix H: References Provided by Domain Experts

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